



Medicaid Health Homes: A new state option can improve patient care, save money, and capture additional federal dollars

As of January 2011, states can qualify for two years of enhanced federal funding to set up health homes to better coordinate the care of Medicaid beneficiaries with chronic physical or mental illnesses. States may elect this new option by filing an amendment to their Medicaid State plan.

Why States Should Take Up the Health Homes Option

Improve Patient Care

Some states have already set up medical homes for Medicaid beneficiaries. These states have found that the care coordination and disease management provided by health homes have improved the quality of life for chronically ill patients. For example, Medicaid enrollees with asthma in North Carolina's medical home program experienced 17 percent fewer asthma-related ER visits and 40 percent fewer asthma-related hospital admissions between fiscal year 2003 and 2006.¹

Save Medicaid Dollars

About five percent of Medicaid beneficiaries account for nearly 60 percent of Medicaid spending.² The health homes state option targets these sickest enrollees — people with chronic conditions — and aims to lower their health care costs by better coordinating their complex care.

Existing Medicaid medical home initiatives have already lowered state costs by reducing unnecessary hospital admissions and ER visits, and CMS encourages these states to design their health home option to complement existing initiatives. The North Carolina medical home program saved the state between \$154 and \$170 million in 2006 alone.³ Illinois saved \$220 million in the first two years that its Medicaid medical home program, Illinois Health Connect, was fully implemented.⁴

Bring New Federal Funds into the State

To help states with the initial costs, CMS will pay 90 percent of health home reimbursements for the first two years. This brings new federal funds into states at a time when they are facing serious budget deficits.

Get Financial Help for Planning

CMS is offering up to \$500,000 per state, available at a state's regular Medicaid matching rate, to support the planning activities for developing a state plan amendment for the health home option.

¹ Kaiser Family Foundation, <http://www.kff.org/medicaid/upload/7899.pdf>

² Center for Health Care Strategies, Inc. http://www.chcs.org/usr_doc/Medicaid_Best_Buys_2010.pdf

³ http://www.communitycarenc.com/PDFDocs/Mercer%20SFY05_06.pdf

⁴ http://articles.chicagotribune.com/2010-08-11/business/ct-biz-0812-notebook-health-20100811_1_medicaid-patients-health-care-medical-home



Designing Consumer-Friendly Health Homes

*Part of a series designed to help
advocates prioritize consumer needs in
the development of Health Homes*

From Families USA • January 2013

Medicaid Health Homes offer states the opportunity and resources to provide coordinated care that can improve the health and well-being of some of their sickest and most vulnerable residents. States have considerable flexibility to identify populations with the greatest need for coordinated care and to design new models of care that address these patients' medical and non-medical needs.

This brief is the second in a series of three pieces that guide advocates as they think about the potential benefits of Health Homes and how they can be designed to most effectively meet patients' needs. It discusses six key decisions that states need to make when setting up Health Homes, and it explains the challenges that state advocates will want to address to ensure that Health Homes improve care.

1. Who gets to enroll in a Health Home?
2. What types of providers can be Health Homes?
3. What standards will providers have to meet to become Health Homes?
4. How will the state define the six Health Home services, and what staff will be needed to provide them?
5. How will health information technology (IT) be used in the Health Home?
6. How will patients be enrolled and engaged in the Health Home?

This piece also includes examples of decisions from the first states to develop Health Homes: Idaho, Iowa, Missouri, New York, North Carolina, Ohio, Oregon, and Rhode Island.

care that integrates medical care, behavioral health care, and social supports, advocates should urge states to develop Health Homes for this population. Missouri, Ohio, and Rhode Island have developed Health Homes for people with mental health or substance use disorders, and several other states are working to do so as well.

Targeting Based on Geography

The Affordable Care Act also allows states to design Health Homes for limited geographic areas. This is a good option for states that want to expand coordinated care but that lack the capacity to launch Health Homes statewide. Advocates should encourage Medicaid officials in states that are reluctant to implement Health Homes statewide to develop them first in counties with high levels of need and providers that have the capacity to become Health Homes. The state can later expand Health Homes more broadly if it chooses, and it will still get two years of enhanced matching funds for Health Home services in counties that did not have Health Homes initially.⁵

► Issues for Advocates to Consider

- Who in the state Medicaid population could benefit most from coordinated care?
- Will the option to develop Health Homes for people with a limited number of conditions or in a targeted geographic area help convince the state to pursue this new care model? If the state limits the population or geographic scope of initial Health Homes, what is its plan to expand or develop new Health Homes in the future?

2. What types of providers can be Health Homes?

Once the state has identified who will be eligible for a Health Home, it must decide what types of providers it will allow to become Health Homes. State advocates should think about which providers are best suited to offer the six Health Home services that are listed in the Affordable Care Act:

1. Comprehensive care management
2. Care coordination
3. Health promotion
4. Comprehensive transitional care
5. Individual and family support services
6. Referrals to community and social support services

For more information on these six services, see page 11.

Although few providers will meet all of these criteria when Health Homes are launched, advocates should encourage states to select providers with the greatest capacity in these areas. Advocates should also push states to specify what additional capabilities these providers will need to develop in order to effectively serve the Health Home population. A timeline for Health Home providers to fill in these gaps should be included in the state plan amendment and in Health Home contracts.

Types of Providers

The early states to develop Health Homes are relying primarily on providers with strong relationships with the Health Home population. These providers include:

■ Safety Net Providers

Many states have designated safety net providers, such as federally qualified health centers (FQHCs) and rural health centers (RHCs), as Health Home providers. Safety net providers may be ideal Health Homes because they already provide care for many Medicaid beneficiaries who would be eligible for Health Homes, they are often located in low-income communities, and they frequently have the cultural and linguistic competence to support the Health Home population.

■ Community Mental Health Centers

Community mental health centers already perform some Health Home functions, including supporting patients' families and connecting vulnerable patients to resources in their community. These providers often have particularly strong relationships with people who have mental illnesses or substance use disorders and who would likely benefit significantly from coordinated care in a Health Home.

Non-Medical Providers as Health Homes

Some non-medical organizations may be good Health Home providers. For example, supportive housing facilities already provide care management, health promotion services, and referrals to community resources for their residents. Lack of stable housing is a significant barrier to health care that can exacerbate chronic conditions, so many people who are eligible for supportive housing would also be eligible for Health Homes. Providing care management that connects residents to primary and behavioral health care services as a part of supportive

housing has successfully improved health status and mental health outcomes, and it has reduced substance use.⁷ Designating supportive housing facilities as Health Homes would build on the strong relationships these facilities already have with Medicaid beneficiaries who would likely be eligible for Health Homes and on their experience with addressing non-medical needs. Selecting these facilities as Health Homes would also enable them to receive Medicaid reimbursement for the care management services they already provide.⁸

- **Lack of Experience with Behavioral Health and Long-Term Supports and Services**
Many managed care organizations lack experience managing behavioral health care and long-term supports and services because these types of care are often excluded from managed care contracts. If a managed care organization has not included behavioral health and long-term supports and services in the past, it should be required to document the steps it will take to ensure that these types of care will be fully integrated into the Health Home and that the appropriate providers are brought into its network.

It is also critical that existing protections for Medicaid consumers in managed care organizations be extended to include Health Homes. Quality reviews will be needed to ensure that Health Homes do not deny necessary care in an effort to save money. Beneficiaries and their families must know their rights and be able to appeal decisions made by the managed care organization. The same internal and external appeals rights that protect Medicaid beneficiaries in managed care should apply to Health Home services, including Medicaid fair hearing protections. Additionally, Health Home providers that contract with managed care organizations should be able to advocate for beneficiaries against the organizations.

► Issues for Advocates to Consider

- Which providers have existing care relationships, care coordination experience, health IT systems, and networks to meet the needs of the Health Home population?
- Will the state allow managed care organizations to be Health Homes, or will it contract with other providers to offer Health Home services? If so, what limitations will need to be addressed?

3. What standards will providers have to meet to become Health Homes?

The state will need to establish a set of standards for determining whether providers can become Health Homes. CMS has not provided final guidance on what standards Health Homes should meet, but it did list 11 functions that Health Home providers are required to perform:¹⁰

1. Provide quality-driven, cost-effective, culturally appropriate, and patient- and family-centered Health Home services.
2. Coordinate and provide access to high-quality health care services that are informed by evidence-based guidelines.

Developing State-Specific Standards

State-specific standards for Health Homes should be based on the needs of the target population, and they should include specific ways to evaluate the systems, protocols, infrastructure, and experience that providers will need to best serve this population.

Advocates should make sure that state standards for provider selection include the following areas that are often overlooked:

- **Behavioral Health**

While the degree of focus on behavioral health requirements will vary depending on whether the Health Home is designed specifically for those with serious mental illness and/or substance use disorders, all Health Homes are responsible for integrating and coordinating behavioral health care. In addition to screening for behavioral health problems, Health Homes should follow best practices for integration with behavioral health providers by, for example, using a “warm hand-off” to help the patient connect with the behavioral health provider through an in-person introduction.

- **Support for Non-Medical Needs**

Referral to community supports and services is another function that is neglected in most medical home models, and it is a critical component of the Health Home model. Advocates should ask how Health Homes will be required to perform services such as following up on referrals to other community organizations and services.

- **Patient Experience**

Health Homes should be required to regularly measure and report patient experience scores and use that feedback to improve how care is delivered. The third brief in this series includes a more detailed discussion of the importance of patient experience measures and different ways to measure patient experience.

Examples of State-Specific Standards

Iowa requires its Health Homes to ensure that each patient has an ongoing relationship with a personal provider and that the patient, the personal provider, and the care team recognize one another as partners in care.

New York requires Health Home providers to guarantee access to a care manager who can provide information and emergency consultation 24 hours a day, seven days a week.

Ohio requires providers to establish partnerships and policies for referrals to and coordination with specialty providers, inpatient facilities, and managed care plans to allow for effective delivery of Health Home services.

could also provide incentives for providers who pursue higher levels of recognition, such as tiered payments. The third brief in this series discusses tiered payments and other financial incentives for provider transformation.

While accreditations and assessments offer an important source of independent evaluation of provider capacity, they have some limits. The PCMH accreditation standards and assessment tools were not developed with complex patients in mind. As a result, they do not adequately address key areas that are essential for successful Health Homes, such as the integration of behavioral health, support for non-medical needs, and the measurement and improvement of patient experiences. Advocates in states that use national accreditation or self-assessment should make sure the state also has strong state standards for these key areas. Additionally, advocates should work with the organizations that have developed accreditation standards or assessments to modify these tools so that they appropriately evaluate these important areas.

► Issues for Advocates to Consider

- What capacities will providers need to serve the Health Home population?
- What requirements should the state have for the integration of behavioral health, support for non-medical needs, and tracking patient experience?
- Would national certification or accreditation be a helpful supplement to state standards? How will the state support providers in obtaining certification or accreditation?

4. How will the state define the six Health Home services, and what staff will be needed to provide them?

The Affordable Care Act lists six services that Health Homes must provide for their enrollees, but it leaves the task of defining what each service means in practical terms and what types of staff members will be needed to deliver these services to the states.

Defining Health Home Services

The following list describes elements that state advocates should look for in the definition of each service. The recommendations for each service are based on the Health Homes that CMS has already approved and on conversations with state advocates who are involved in Health Home development:

■ Comprehensive Care Management

Comprehensive care management includes identifying individuals who would benefit from a Health Home, assessing patients' medical and non-medical needs, developing patient-centered care plans, and assigning roles in patient care. Patients and/or caregivers should be actively involved in the development of the care plan, which

■ Referral to Community and Social Support Services

Referral to community and social support services helps patients to obtain and maintain the non-medical resources they need to lead healthy lives. Health Homes should refer patients to resources such as long-term services and supports, disability benefits, nutrition assistance, education, housing, and legal services. Such referrals must go beyond handing the patient a list of local service providers—Health Home staff should facilitate connections with other service providers, follow up with the patient, and address barriers to obtaining services.

Patient-centered care engages the patient and her caregivers as active participants in care. The provider's role is to give the patient a thorough explanation of her care options and help her identify what will work best, rather than making decisions for the patient. Patient-centered care recognizes that the effectiveness of treatment, particularly of chronic disease, depends in large part on the patient's self-management of her illnesses. Patient buy-in can dramatically improve the likelihood that treatment will be successful. Patient-centered care also requires a provider to determine what, if any, barriers a patient may encounter when trying to follow through with treatment or improve her health. State advocates should evaluate each service definition by how well it meets these goals of patient-centered care.

Members of the Care Team

Each Health Home patient will need a team to oversee his or her care that includes medical and non-medical Health Home staff, family and caregivers, and the patient. Because no two patients' needs will be the same, there is no one-size-fits-all team. As states develop requirements for what types of providers should be in a Health Home and what the six Health Home services include, advocates should make sure that Health Homes are required to develop teams that are tailored to each individual patient, based on a thorough assessment of her medical and non-medical needs.¹⁹ Key providers that will be a part of most teams include:

■ A Primary Care Provider

All Health Homes will want to include a primary care provider as a central member of the team. To ease staffing burdens, particularly on Health Homes that are not based in primary care practices, some states are allowing non-physicians, such as nurse practitioners, to be designated as primary care providers.²⁰

■ A Behavioral Health Provider or Consultant

Patients with multiple chronic illnesses also have higher rates of depression and other mental health problems. All Health Homes, whether or not they are focused on those with serious mental illnesses, should either include a behavioral health provider or have access to a consultant who can give recommendations or referrals for behavioral health needs.

5. How will health IT be used in the Health Home?

A key component of care coordination that runs through all six Health Home services is ensuring that everyone who is involved in a patient's care has the same timely, accurate information about the patient and can communicate easily. Health IT provides powerful tools to facilitate communication and information-sharing, and it is a key part of a successful Health Home. Electronic health records (EHRs) are the most common form of health IT that is used in care coordination, and they can give all providers access to a patient's health history, care plan, medication list, allergies, test results, and current treatments.

Robust health IT systems will benefit Health Homes and their patients in a number of ways:

- **Easier Care Coordination**
Coordinating care for patients with multiple providers across care settings requires a central source of patient information. All providers should have access to their patients' care plans and notes from other providers about medications, test results, courses of treatment, and the steps being taken to meet the patient's non-medical needs. This can cut down on redundant testing and adverse drug interactions, and it gives each provider a more complete picture of the patient's needs.
- **Improved Quality of Care**
Health Homes can use a number of tools to help proactively ensure that patients are receiving the care they need. Health IT tools can alert the care manager when each of his diabetic patients needs a hemoglobin A1c test, for example, or they can remind him to make a follow-up home visit to a patient who was recently discharged from the hospital.
- **More Accessible Provider Tools and Resources**
Health IT can support providers during visits with patients. Tools that are built in to an electronic health records program can aid in the diagnosis, care planning, and treatment of patients with complex conditions. For example, such a tool could alert a physician to a potential interaction among the medicines a patient is currently taking and a new drug the physician is considering prescribing. Lists of community support services could also be made available to the provider during a visit.
- **Performance and Quality Tracking**
Health Homes are expected to perform well on key quality measures and show ongoing improvement over time. Good electronic records of patients' health care and outcomes allow providers to monitor their progress, identify best practices, and correct problems along the way. The third brief in this series discusses how Health Homes should measure performance and quality in more detail.

6. How will patients be enrolled and engaged in the Health Home?

States must decide how best to enroll eligible patients in Health Homes while ensuring continuity of care and preserving a patient's ability to choose the care that works best for her.

Enrollment

States have taken two approaches to enrolling eligible patients in Health Homes. Health Home enrollment can be active, where potentially eligible individuals sign themselves up, or passive, where the state automatically assigns enrollees to Health Homes. Each option presents challenges that need to be addressed as enrollment procedures are developed. Advocates should support whichever method will ensure that all eligible patients are aware of Health Homes and understand what they are while offering the flexibility for patients to choose the care that best meets their needs.

- **Active Enrollment (also known as opt-in or voluntary enrollment)**

Active enrollment requires the patient to make an affirmative decision to select and enroll in a Health Home. This method of enrollment helps ensure continuity of care, since patients will usually sign up for a Health Home where they already receive care. A voluntary enrollment process also gives Health Homes an incentive to provide the services that patients want and need, since patients can always “vote with their feet” by leaving the Health Home.

If done poorly, however, active enrollment can lead to low participation among eligible patients, particularly those who don't have ongoing relationships with providers who may need care coordination the most. Advocates should push states that use active enrollment to work with providers and trusted community-based organizations to publicize the Health Home program, educate beneficiaries about their options, and help them select and enroll in a Health Home that works best for them.

- **Passive Enrollment (also known as opt-out)**

Passive enrollment is a process in which the state automatically assigns eligible individuals to Health Homes, but it gives each beneficiary the option to select another Health Home or to opt out of being in a Health Home altogether. Health Home enrollment becomes the default for eligible Medicaid beneficiaries, leading to higher levels of participation.

If not done properly, passive enrollment can disrupt ongoing courses of treatment or existing patient-provider relationships. Passive enrollment should be paired with a robust assignment process that uses Medicaid claims history to assign each patient to the Health Home where he or she currently receives care. Passive enrollment also needs strong transition protections. If the Health Home to which the beneficiary is

■ Informational Mailings

Prior to enrollment in a Health Home, the patient should receive a clear, easy-to-read description of what a Health Home is and what its benefits are. For example, in its draft state plan amendment, West Virginia proposes that notifications to individuals who are automatically enrolled in a Health Home include a description of what the Health Home does; an explanation of the person's ability to choose another Health Home; a list of all Health Homes in the state; information on how to opt out or switch Health Home providers; and an assurance that if the person chooses not to participate in a Health Home, his or her current care will not be jeopardized.²⁵ Information that is sent to those who are assigned to a Health Home must make this opt-out provision clear.

■ Community Forums

Community forums can be a helpful way to give caregivers and potentially eligible patients information about what a Health Home is, and it allows them to interact with Health Home staff and to ask questions. Community-based organizations that have strong relationships with people who may be eligible for Health Homes would be ideal hosts for these forums.

Advocates should make sure that states incorporate the needs of people with limited English proficiency, low literacy, and disabilities into their enrollment procedures. Best practices for designing notifications include making sure they are at a 6th grade reading level or lower; translating notifications into all languages that are spoken by either 5 percent of the enrollee population or 500 people, whichever is less; and field testing notifications with the target population.²⁶

Engagement

Health Homes have new roles for not just providers, but for patients as well. Successful Health Home care requires the active participation of the patient and her caregivers. Enlisting patients and their families as members of the care team requires clear communication from the Health Home about the patient's role and responsibilities. Trusted community-based organizations that have strong relationships with the patient population can also play an important role in patient education. For example, the National Alliance on Mental Illness (NAMI) of Ohio is working with the state Department of Mental Health to develop educational materials and training for those who are eligible for Ohio's community behavioral health center Health Homes. NAMI Ohio's local affiliates will use these materials to educate Health Home patients.

Endnotes

- ¹ For a list of the conditions targeted by the first states to develop Health Homes, see the "Health Homes: Summary of Key Details" chart at the end of the first brief in this series, *Health Homes in Medicaid: Challenges and Opportunities for Advocates*, available online at <http://familiesusa2.org/assets/pdfs/health-system-reform/Health-Homes-in-Medicaid.pdf>.
- ² The North Carolina Health Home state plan amendment is available online at <http://www.ncdhhs.gov/dma/plan/HealthHomeApprovedSPA-Effective10012011.pdf>.
- ³ Stephen Gough and Robert Peveler, "Diabetes and Its Prevention: Practical Solutions for People with Schizophrenia," *The British Journal of Psychiatry* 184 (2004): 106-111, available online at <http://bjp.rcpsych.org/content/184/47/s106.full>.
- ⁴ Joe Parks, Dale Svendsen, Patricia Singer, and Mary Ellen Foti (eds), *Morbidity and Mortality in People with Serious Mental Illness* (Alexandria, VA: National Association of State Mental Health Program Directors, 2006), available online at http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Technical%20Report%20on%20Morbidity%20and%20Mortality%20-%20Final%2011-06.pdf.
- ⁵ Each new Health Home qualifies for its own two-year enhanced match period. For more information, see Sarah Baggé, *Health Homes in Medicaid: Challenges and Opportunities for Advocates* (Washington: Families USA, November 2012), available online at <http://familiesusa2.org/assets/pdfs/health-system-reform/Health-Homes-in-Medicaid.pdf>.
- ⁶ The HITECH Act established incentive payments for certain hospitals and individual Medicaid providers who adopt and demonstrate meaningful use of EHRs. Eligible providers can receive up to \$63,750 per year for EHR use. For more information, see <http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/EHRIncentivePrograms/>.
- ⁷ Michael Nardone, Richard Cho, and Kathy Moses, *Medicaid-Financed Services in Supportive Housing for High-Need Homeless Beneficiaries: The Business Case* (Hamilton, NJ: Center for Health Care Strategies, 2012), available online at http://www.chcs.org/publications3960/publications_show.htm?doc_id=1261378#.UFDxnK604QM.
- ⁸ Corporation for Supportive Housing, *The Role of Supportive Housing Providers: Creating Health Care Homes for Chronically Ill Residents* (New York: Corporation for Supportive Housing, July 2011), available online at http://www.csh.org/wp-content/uploads/2011/12/Report_HealthHomesOption.pdf.
- ⁹ Deborah Peikes, Arnold Chen, Jennifer Schore, and Randall Brown, "Effects of Care Coordination on Hospitalization, Quality of Care, and Health Care Expenditures among Medicare Beneficiaries," *Journal of the American Medical Association* 301, no. 6 (2009): 603-618, available online at <http://jama.jamanetwork.com/article.aspx?articleid=183370#RESULTS>.
- ¹⁰ Centers for Medicare and Medicaid Services, *State Medicaid Director Letter Re: Health Homes for Enrollees with Chronic Conditions* (Baltimore: Department of Health and Human Services, Nov. 16, 2010), available online at <http://downloads.cms.gov/cmsgov/archived-downloads/SMDI/downloads/SMD10024.pdf>.
- ¹¹ Idaho's Health Homes website indicates that Idaho's draft state plan amendment includes the requirement that Health Homes reach at least Level 1 NCQA certification by the second year of Health Home participation. Iowa's state plan amendment indicates that the state will also likely require NCQA accreditation. Missouri is requiring its chronic disease Health Homes to submit an application for NCQA recognition within 18 months of offering Health Home services and to achieve PCMH Level 1 standards.
- ¹² For more on the NCQA PCMH standards, see <http://www.ncqa.org/Programs/Recognition/PatientCenteredMedicalHomePCMH.aspx>.
- ¹³ The Joint Commission offers Primary Care Medical Home Certification. For more information, see <http://www.jointcommission.org/accreditation/pchi.aspx>.
- ¹⁴ For more information on Medical Home certification by the Accreditation Association for Ambulatory Health Care, see <http://www.aaahc.org/en/accreditation/primary-care-medical-home/>.
- ¹⁵ Information about URAC's Patient-Centered Health Care Home certification is available online at <https://www.urac.org/pchch/>.
- ¹⁶ Ohio's Health Home state plan amendment is available online at http://www.chcs.org/usr_doc/Medicaid_Model_Data_Lab.pdf.
- ¹⁷ For a thorough comparison of available PCMH accreditation models, see Rachel A. Burton, Kelly J. Devers, and Robert A. Berenson, *Patient-Centered Medical Home Recognition Tools: A Comparison of Ten Surveys' Content and Operational Details* (Washington: Urban Institute, 2012) available online at <http://www.urban.org/uploadedpdf/412338-patient-centered-medical-home-rec-tools.pdf>.
- ¹⁸ For more information about TransforMED, see <http://www.transformed.com/>.

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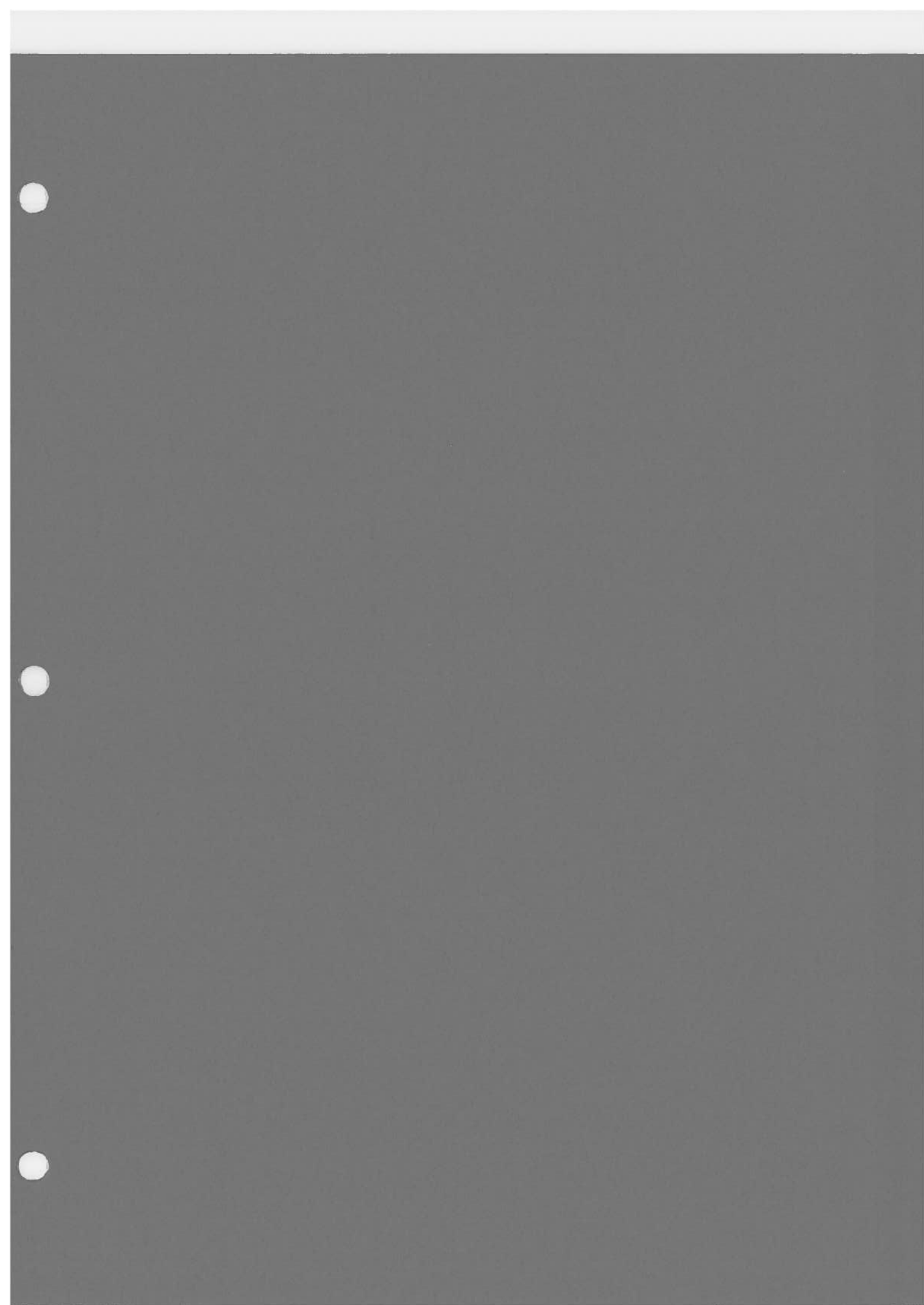
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Five Key Facts About the Delivery and Financing of Long-Term Services and Supports

Fact #1: People of All Ages Require Long-Term Services and Supports

As a result of physical limitations, cognitive impairments, mental illness, and/or a disabling chronic condition, an individual may need long-term assistance for several months or years. Assistance can include help with completing daily self-care tasks, such as bathing, dressing, or managing prescription medications, and also with completing errands, such as grocery shopping or traveling to doctor appointments. Those with severely disabling chronic conditions often require more extensive acute care and long-term services and supports (LTSS) as they age. The 2011 U.S. Census Bureau *American Community Survey* estimates that:



- 8 million people experience difficulty with self-care (i.e., completing “activities of daily living”)
- 13 million adults experience difficulty with living independently
- 14 million children and adults have difficulty remembering, concentrating, or making decisions
- 20 million children and adults experience difficulty with walking or climbing stairs¹

Fact #2: Many People Who Need Long-Term Services and Supports Rely on Unpaid, Informal Care

Family caregivers have traditionally provided informal assistance with personal care and household chores, but in many cases informal caregiving now includes skilled medical/nursing care tasks such as meal preparation for a special diet, wound care, and care coordination. The majority of family members providing care to people with multiple chronic physical and cognitive conditions were:

- female (58%)
- age 50 or above (66%)
- caring for a parent (38%)
- providing care for three or more years (44%)
- employed outside of the home (47%) and making less than \$50,000 annually (48%)

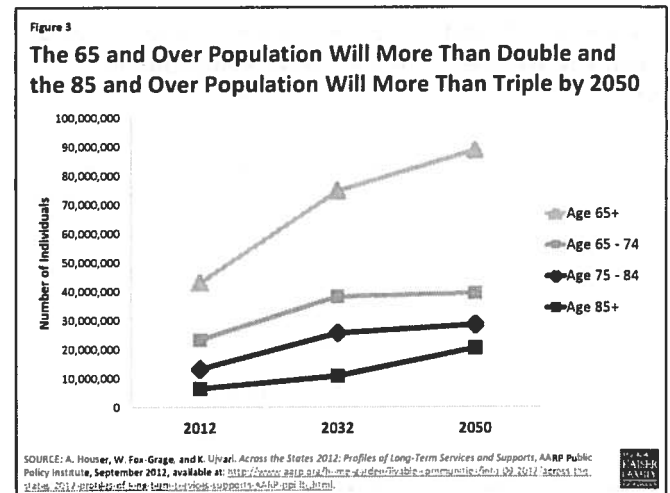


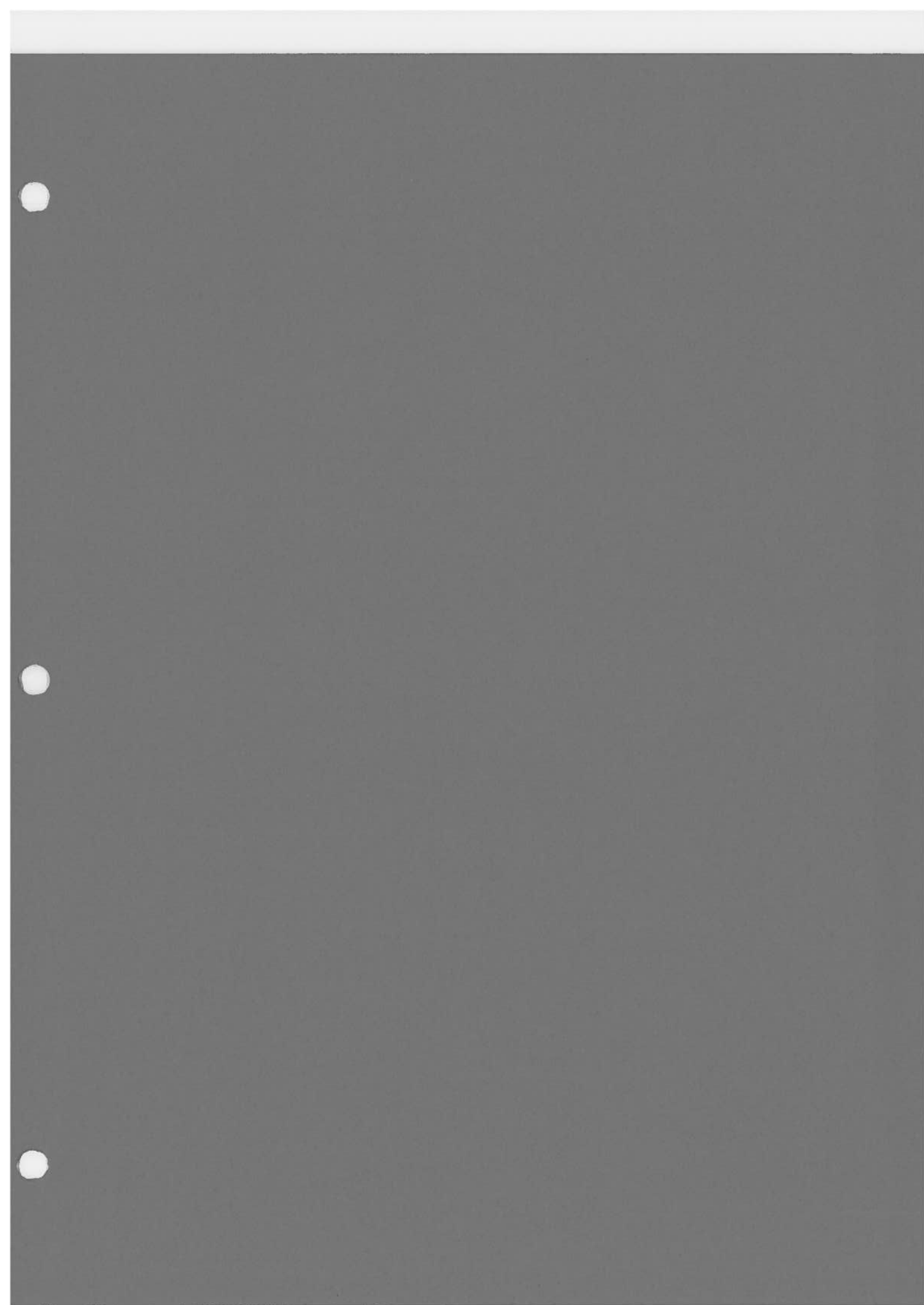
Most family caregivers are willing to provide care for their family members and friends, but the caregiving experience can be very demanding, leading to undesirable outcomes such as chronic stress or financial strain.²

the various LTSS options on spending and beneficiary outcomes.⁷

Fact #5: With the Aging of America, the Demand for Long-Term Services and Supports is Expected to Increase in the Coming Decades

The U.S. will experience a demographic shift by age in the coming decades as a result of the “Baby Boomers” reaching older adulthood, increased life expectancy, and advances in medicine and medical technology. The majority of Americans aged 65 and over will have long-term care needs (70% of “Baby Boomers” can expect to use some form of long-term care during their lives); the population that is most likely to need LTSS—individuals aged 85 and over—is expected to increase by almost 70 percent in the next 20 years (Figure 3).⁸ In the face of increased demand for LTSS, states and the nation will be challenged to find innovative ways to deliver high quality, person-centered LTSS, reduce unmet long-term care needs and HCBS workforce shortages, increase accessible and affordable community-based housing options, and strengthen community-based provider and resource networks.





June 2012

Questions and Answers on Health Homes

What are Health Homes?

Health homes are designed to be person-centered systems of care that facilitate access to and coordination of the full array of primary and acute physical health services, behavioral health care, and long-term community-based services and supports. The model aims to improve health care quality and clinical outcomes as well as the patient care experience, while also reducing per capita costs through more cost-effective care.

What are Health Homes versus Medical Homes?

The health home model of service delivery expands on the traditional medical home models that many states have developed in their Medicaid programs, by building additional linkages and enhancing coordination and integration of medical and behavioral health care to better meet the needs of people with multiple chronic illnesses.

What is Medicaid's New "Health Home" Option?

Many Medicaid beneficiaries suffer from multiple or severe chronic conditions and could potentially benefit from better coordination and management of the health and long-term services they receive, often in a disjointed or fragmented way. An increasing number of states have been adopting strategies to achieve such improvements, such as health homes and enhanced primary care case management.

Who can qualify for Medicaid health home services?

To be eligible for health home services, Medicaid beneficiaries must have at least two chronic conditions, including asthma, diabetes, heart disease, obesity, mental condition, and substance abuse disorder; one chronic condition and be at risk for another; or one serious and persistent mental health condition. Both children and adults who meet these criteria are eligible for health home services; individuals who are dually eligible for Medicaid and Medicare cannot be excluded.

What are specific health home services?

Health home services include: comprehensive care management; care coordination and health promotion, comprehensive transitional care from inpatient to other settings, including appropriate follow-up; individual and family support; referral to community and social support services, if relevant; and the use of health information technology (HIT) to link services.

What funding is available to help support state planning activities?

CMS will authorize state applicants to spend up to \$500,000 of Medicaid funding for planning activities related to the development of a health home SPA; state spending for this purpose will be matched at the state's regular FMAP rate for Medicaid services. The funds can be spent for activities such as hiring personnel to determine feasibility and develop a health home program, outreach to obtain consumer and provider feedback, training and consultation, systems development and other infrastructure-building tasks, and associated travel. To receive funding, available beginning January 1, 2011, a state must submit a Letter of Request to CMS, outlining its planning activities.

How will Health Homes be evaluated?

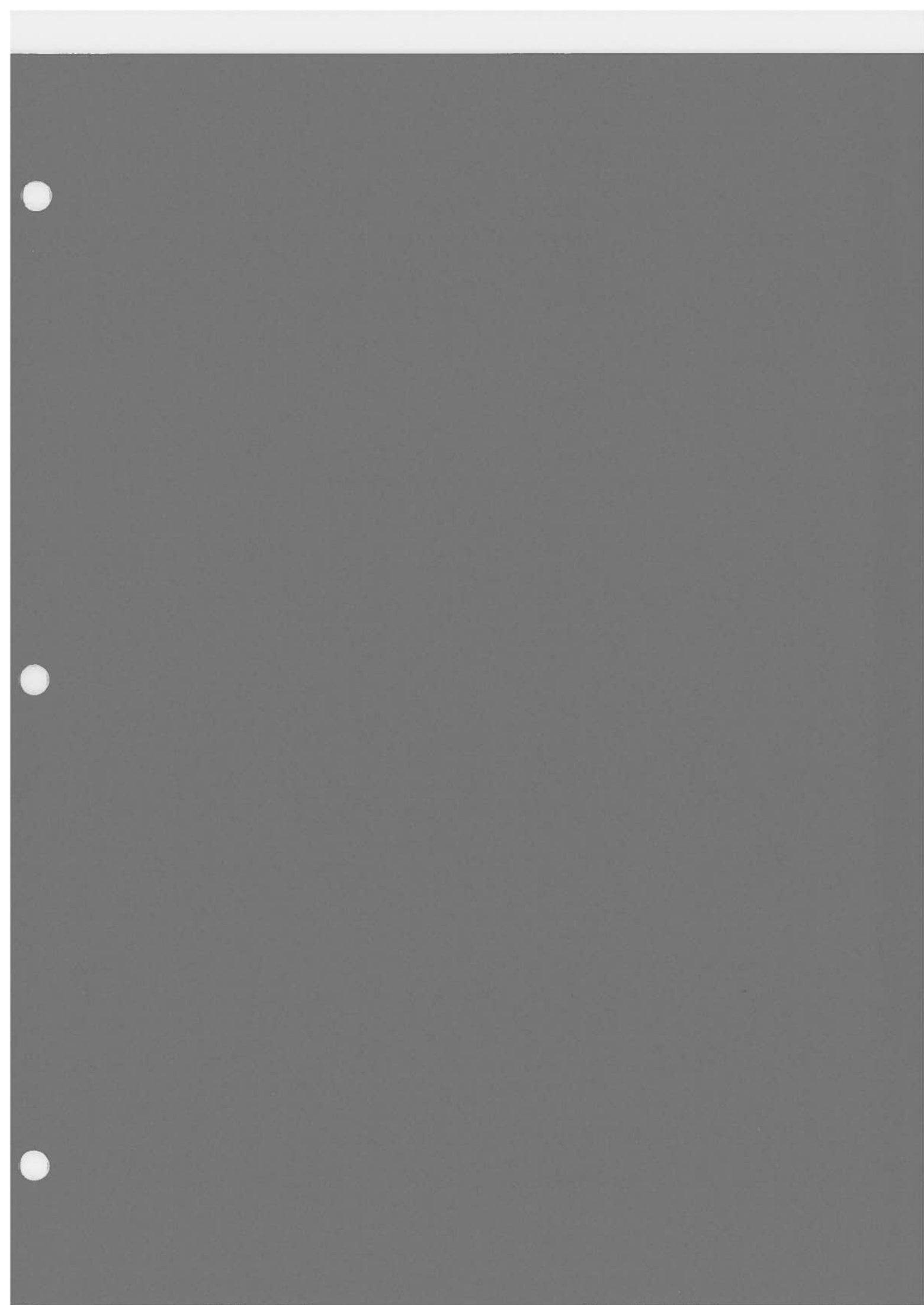
HHS must survey all states that elect the home health option by January 1, 2014 to prepare an interim report to Congress. The HHS Secretary must contract for an independent evaluation of the health home model and report to Congress by January 1, 2017. States must cooperate with the entity conducting the evaluation. CMS will provide further guidance on the evaluation design to the states implementing the health home option. The evaluation must address the effect of the model on reducing hospital readmissions, emergency room visits and admissions to skilled nursing facilities. Findings from the evaluation will be used to drive system-wide improvement in the delivery of health home services.

How will Health Homes affect Behavioral Healthcare?

In 2008, NASMHPD called for the creation of a "patient-centered medical home" for individuals who have mental illnesses, as these consumers so often have co-morbid substance use and other serious medical conditions such as diabetes and heart conditions.

The call is contained in a report, *"Measurement of Health Status for People with Serious Mental Illnesses."* The report describes the health home as a platform for bringing together a primary care/physical health provider and specialty behavioral health services practitioners to provide collaborative care using disease management strategies based on the chronic care model.

SBHAs should assure that financing mechanisms align with, and promote, a single, integrated point of clinical responsibility for the individual, moving away from fragmented, fee-for-service reimbursement.



January 2011

Medicaid's New "Health Home" Option

Many Medicaid beneficiaries suffer from multiple or severe chronic conditions and could potentially benefit from better coordination and management of the health and long-term services they receive, often in a disjointed or fragmented way. An increasing number of states have been adopting strategies to achieve such improvements, such as medical homes and enhanced primary care case management. The Patient Protection and Affordable Care Act (ACA), the health reform law enacted on March 23, 2010, provided states with a new Medicaid option along these lines – to provide "health home" services for enrollees with chronic conditions. Further, to encourage states to take up the new option, ACA authorized a temporary 90% federal match rate (FMAP) for health home services specified in the law. The health home option, established by 2703 of ACA, became available to states on January 1, 2011.

Health homes are designed to be person-centered systems of care that facilitate access to and coordination of the full array of primary and acute physical health services, behavioral health care, and long-term community-based services and supports. The health home model of service delivery expands on the traditional medical home models that many states have developed in their Medicaid programs, by building additional linkages and enhancing coordination and integration of medical and behavioral health care to better meet the needs of people with multiple chronic illnesses. The model aims to improve health care quality and clinical outcomes as well as the patient care experience, while also reducing per capita costs through more cost-effective care.

On November 16, 2010, CMS issued guidance to the states, outlining the requirements, choices, funding opportunities, and expectations that states interested in adopting the health home option through a state plan amendment (SPA) will wish to consider. CMS encourages states with existing or planned medical home initiatives to compare those programs to the definition of health homes under ACA and to design their health homes to complement those initiatives. Key information about the new health home option and highlights of the CMS guidance are summarized below.

Who can qualify for Medicaid health home services?

To be eligible for health home services, Medicaid beneficiaries must have at least two chronic conditions, including asthma, diabetes, heart disease, obesity, mental condition, and substance abuse disorder; one chronic condition and be at risk for another; or one serious and persistent mental health condition. Both children and adults who meet these criteria are eligible for health home services; individuals who are dually eligible for Medicaid and Medicare cannot be excluded. States can target health home services to those with particular chronic conditions or those with higher numbers or severity of chronic or mental health conditions. In addition, because the Medicaid "comparability" requirement is waived, states can offer health home services in a different amount, duration, and scope than services provided to individuals not in the health home population.

What are health home services?

Health home services that are eligible for the 90% FMAP include: comprehensive care management; care coordination and health promotion, comprehensive transitional care from inpatient to other settings, including appropriate follow-up; individual and family support; referral to community and social support services, if relevant; and the use of health information technology (HIT) to link services. These services must be provided by a "health home provider arrangement," as described next.

What funding is available to help support state planning activities?

CMS will authorize state applicants to spend up to \$500,000 of Medicaid funding for planning activities related to the development of a health home SPA; state spending for this purpose will be matched at the state's regular FMAP rate for Medicaid services. The funds can be spent for activities such as hiring personnel to determine feasibility and develop a health home program, outreach to obtain consumer and provider feedback, training and consultation, systems development and other infrastructure-building tasks, and associated travel. To receive funding, available beginning January 1, 2011, a state must submit a Letter of Request to CMS, outlining its planning activities.

What state monitoring and reporting requirements apply?

States are expected to collect and report information required for the comprehensive evaluation of the health home model; CMS recommends that states collect individual-level data to permit comparative analyses of the effect of the health home model across Medicaid sub-populations, as well as comparisons between those who do and do not receive health home services. States must track avoidable hospital readmissions, calculate savings due to improved care coordination and disease management, and monitor the use of HIT; they are also required to track emergency department visits and skilled nursing facility admissions. CMS plans to specify a uniform methodology for tracking avoidable hospital readmissions and calculating savings.

States must also report on quality measures. CMS will provide further guidance on these requirements and plans to develop a core set of quality measures for assessing health homes, in consultation with the states and others. Until then, states are expected to define the measures they will use, which should capture information on clinical outcomes, experience of care outcomes, and quality of care outcomes.

How will health homes be evaluated?

HHS must survey all states that elect the home health option by January 1, 2014 to prepare an interim report to Congress. The HHS Secretary must contract for an independent evaluation of the health home model and report to Congress by January 1, 2017, and states must cooperate with the entity conducting the evaluation. CMS will provide further guidance on the evaluation design to the states implementing the health home option. The evaluation must address the effect of the model on reducing hospital readmissions, emergency room visits and admissions to skilled nursing facilities. Findings from the evaluation will be used to drive system-wide improvement in the delivery of health home services.

Looking ahead

As states continue to move forward to improve the coordination and management of care for Medicaid enrollees – especially those with the most complex and expensive needs – the health home option offers them a new strategy, along with significant federal support in the form of a 90% match for these services for two years. At a time when interest in creating a high-performing health care system has never been greater, but the recessionary demands on state resources remain difficult, the health home option offers states a programmatic and funding opportunity that addresses both these important realities.

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The Kaiser Family Foundation is a non-profit private operating foundation, based in Menlo Park, California, dedicated to producing and communicating the best possible analysis and information on health issues.

Developing Health Homes to Effectively Serve Medicare-Medicaid Enrollees

By Alice Lind and Allison Hamblin, Center for Health Care Strategies, and Brendan Hogan and Beth Waldman, Bailit Health Purchasing

The new Medicaid health home state plan option offers comprehensive, person-centered care for Medicaid beneficiaries with chronic conditions through providers who help to coordinate primary and acute care, behavioral health care, and long-term services and supports (LTSS). Medicare-Medicaid enrollees are particularly well suited to benefit from health home arrangements because of the prevalence of multiple chronic conditions in this population:

- More than 60 percent have multiple physical conditions;
- 20 percent have multiple mental health conditions; and
- 38 percent have both physical and mental health conditions.¹

The care provided to these individuals is often fragmented and poorly coordinated leading to lower quality of care and increased costs. For example, Medicare-Medicaid enrollees age 64-75 have avoidable hospitalization rates that are two to four times those of non-dual Medicare beneficiaries.²

States electing to provide health home services may not exclude Medicare-Medicaid enrollees.³ However, because Medicare pays for most of their acute care services (primarily hospital and physician services and prescription drugs), and because states have had limited access to data and information on these Medicare services, including Medicare-Medicaid enrollees in the design of health homes poses a number of challenges. This brief from the *Integrated Care Resource Center* (ICRC) outlines some of the challenges states may face related to serving Medicare-Medicaid enrollees in health homes, as well as considerations for developing health home programs that effectively meet the needs of this population.

Challenge #1: Managing Service Coordination Needs

Including Medicare-Medicaid enrollees in health homes necessitates that these programs are effectively designed to address the broad needs of this heterogeneous population, including LTSS and behavioral health.

IN BRIEF: The service needs of Medicare-Medicaid enrollees (also known as "dual eligibles") make them particularly well suited for inclusion in the programs being developed under the new Medicaid health home state plan option under section 2703 of the Affordable Care Act (ACA). Including them in these programs offers potential benefits for both enrollees and states. However, their inclusion may pose several operational challenges for states, since most of their primary and acute care services are provided through Medicare rather than Medicaid. This technical assistance brief outlines the challenges facing states when including Medicare-Medicaid enrollees in health homes and details considerations for developing programs that will best meet the needs of this population.

Considerations

Long-Term Services and Supports

To ensure the effectiveness of health home models for Medicare-Medicaid enrollees, it will be particularly important to include mechanisms for addressing and coordinating enrollees' LTSS needs, in addition to their medical and behavioral health conditions. Long-term services and supports account for 69 percent of Medicaid spending for Medicare-Medicaid enrollees.⁴ In addition to ensuring the provision of these services, it also is essential to develop connections between the health home and LTSS providers. This population uses a wide array of LTSS provided by nursing homes, home health agencies (HHA), area agencies on aging (AAA), aging and disability resource centers (ADRCs), and developmental disabilities services agencies, among others.

There are a number of examples of this coordination happening successfully in practice today. CareOregon health plan enrolls dual eligibles through its Medicare Special Needs Plan (SNP) contract and enrolls Medicaid-only members under its Care Coordination Organization contract with the state of Oregon. It piloted a model of shared information and care planning with the LTSS system⁵ and addressed the

arrangements) can centralize some aspects of care management for Medicare-Medicaid enrollees at the health plan level and require the health plan be responsible for ensuring that health home activities address LTSS service needs; and

- States can contract with LTSS providers to serve as the health home for beneficiaries with relevant care needs, including Medicare-Medicaid enrollees.

Behavioral Health

Because many Medicare-Medicaid enrollees have comorbid physical and behavioral health conditions, it is important to ensure the coordination, and to the extent possible, integration of medical care and behavioral health services within the health home model. Given the explicit opportunity under statute to target health home services to individuals with serious mental illness (SMI), many states are developing specialized health home models to serve this population. For example, Missouri and Rhode Island both have approved health home programs that serve individuals with SMI statewide. In both states, health homes are situated in community mental health centers, with specific requirements to promote primary care integration – in some cases including co-location of primary care professionals within the mental health setting. These models have a strong potential to improve coordination between physical and behavioral health services, and warrant specific consideration given that the SMI population includes substantial numbers of Medicare-Medicaid enrollees.¹⁰

Challenge #2: Leveraging Existing Care Management Resources

Medicare-Medicaid enrollees who frequently access LTSS and behavioral health services often have care managers for each of these specific services. As states are prohibited from paying for duplicate care management activities, they must identify ways to leverage existing care management structures in the development of their health home approach. States applying for new LTSS

funding opportunities under the ACA must ensure that care management services are on a pathway to being “conflict-free” (the entity providing case management services or conducting eligibility determinations is separate from the entity directly providing services). States may be motivated to comply with this requirement as they see the value of reducing the numbers of different case managers involved with any one individual. If health homes add a new care manager to the mix, it becomes even more important to create systems that decrease unnecessary complexity. For example, in designing Iowa’s health home program, the state created procedures specifically to avoid duplication of care management services. In Iowa an individual receiving care through a health home practice receives all care management through that practice.¹¹ In North Carolina, case management for the state’s health home program comes from its existing care management program, Community Care of North Carolina, whose activities include targeted education and care coordination.¹²

Considerations

Traditional LTSS providers, including HHAs, AAAs, and ADRCs, play an essential role in the overall care of all Medicare-Medicaid enrollees, but particularly in providing services and care coordination assistance through community-based services for individuals with disabilities and frail elders. As states look to develop health home models that include Medicare-Medicaid enrollees, it is important to consider how these traditional LTSS providers can continue to participate in the provision of care. Behavioral health case managers are also an important resource that states should consider including as part of the health home team.

Describing Care Coordination Requirements

States’ proposals for health home state plan amendments must include definitions of the six required health home services, including comprehensive care management and care coordination. Similarly, states proposing to serve Medicare-Medicaid enrollees through the Medicare-Medicaid Financial Alignment Demonstration must describe how their

Health homes situated in community mental health centers that focus on coordinating physical and behavioral health services, may warrant closer consideration given that the population with serious mental illness includes substantial numbers of Medicare-Medicaid enrollees.

enrollees. For example, among those with serious mental illness, states may achieve significant savings in Medicaid-funded behavioral health services as a result of improved care management and care coordination. Similarly, states may also benefit from reductions in LTSS expenditures. To the extent that health homes effectively improve coordination and communication with LTSS providers – for example, improving transitions between settings of care and helping beneficiaries to prevent incidents such as falls that can lead to nursing home stays – health homes could achieve savings for Medicare-Medicaid enrollees that flow directly to Medicaid.

States that are developing health homes as part of either a capitated or a managed fee-for-service model Financial Alignment Demonstration through the Medicare-Medicaid Coordination Office and the Center for Medicare & Medicaid Innovation have the opportunity to share in savings. Incorporating health homes in these demonstrations can make the investment in health home services for Medicare-Medicaid enrollees much more attractive for states.

A number of states, including Missouri and Washington, have included health home-based models in their proposals to integrate care for Medicare-Medicaid enrollees.¹⁴

Challenge #4: Accessing Medicare Data and Information

It has been difficult for states to access and integrate historical Medicare data and real-time information on Medicare-covered services for Medicare-Medicaid enrollees. Access to historical data is very important for program design and the availability of real-time information is vital for care coordination and care transitions.

Considerations

Use of Medicare Data for Program Design

As states design health home models, it is important to understand patterns of Medicare-covered service use by the Medicare-Medicaid enrollee population to support effective targeting of individuals

who could benefit from the enhanced care coordination and care management services that such models provide. For example, health home eligibility is based on the presence of specified chronic conditions. Access to Medicare data would enable more comprehensive identification of enrollees with the targeted conditions, as these diagnoses may not always be represented in their Medicaid claims.

To assist states in requesting Medicare data, CMS has established the State Data Resource Center (SDRC) to facilitate state access to and use of Medicare data in care coordination of Medicare-Medicaid enrollees. The SDRC provides guidance to states on how to address limitations in CMS data, describes how to use Medicare data for care coordination efforts, and assists with the process of obtaining Medicare data.¹⁵

Use of Medicare Data and Information for Care Coordination

In addition to using data to identify beneficiaries for health home enrollment, states are also sharing data with providers to facilitate care coordination. In some cases, states are providing these data directly to the health homes; in other cases, they are requiring managed care organizations or other partners to make these data available to the health homes on a regular basis. For Medicare-Medicaid enrollees, the utility of claims data for care coordination relies on having access to both Medicare and Medicaid data, as Medicaid claims alone do not present the full picture of health needs or service utilization for these enrollees.

More importantly, real-time information on hospital and emergency room admissions and discharges, which is crucial for effective care coordination at the individual level, cannot be obtained from claims data, since providers often do not submit these claims for payment until weeks or months after the service is provided. Real-time information on these admissions and discharges must be obtained directly from hospitals for both Medicaid and Medicare-Medicaid enrollees.

For example, North Carolina is leveraging a system originally developed for bioterrorism alert purposes to share real-time information on hospitalizations with health home

Health homes that effectively improve coordination and communication with long-term services and supports and behavioral health providers could achieve savings for Medicare-Medicaid enrollees that flow directly to Medicaid.

needed to collect the necessary data for Medicare-Medicaid enrollees.

Considerations

The goals of both health homes and the financial alignment demonstrations are similar: to improve service delivery for those beneficiaries at risk for poor health outcomes through care management and coordination. Related to those goals, performance measures must be in place and monitored regularly. This is especially important because both initiatives are relatively new in design, and CMS is keenly interested in determining whether states' varied approaches result in the desired outcomes for beneficiaries. To assess the benefits of health homes, states are required to develop program goals, as well as quality measures that support those goals.

In addition to state-developed measures, CMS has developed a core set of eight quality measures for which states must report data, as described in a January 2013 State Medicaid Director letter (available at <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-001.pdf>):

- Adult BMI Assessment;
- Ambulatory Care-Sensitive Admission;
- Care Transition – Transition Record Transmitted to Health Care Professional;
- Follow-Up After Hospitalization for Mental Illness;
- Plan All-Cause Readmission;
- Screening for Clinical Depression and Follow-Up Plan;
- Initiation and Engagement of Alcohol and Other Drug Dependence Treatment; and
- Controlling High Blood Pressure.

The core health home measures were developed with an eye toward alignment of the required measures across all CMS programs. As such, all but one of the core health home measures (ambulatory care-sensitive admission) aligns with the core set of Medicaid Adult Health Care Quality measures, and two of the measures are the same as those identified specifically for the

Medicare-Medicaid population, listed below.

For Medicare-Medicaid enrollee demonstrations, a national evaluation contractor will collect data from states to report on a set of common quality measures, but the states are expected to additionally track performance measures that are specific to their goals and the individual program design. States should ensure that their health home measures accommodate the needs of the Medicare-Medicaid enrollee population by: 1) tracking measures for which they have the necessary data available, or for which they can require data to be reported; and 2) selecting some measures that reflect the health needs and service use of Medicare-Medicaid enrollees.

Examples of important measures for the Medicare-Medicaid enrollee population include these identified by the National Quality Forum's Measurement Application Partnership (MAP) Dual Eligible Workgroup:¹⁹

- Screening for Clinical Depression and Follow-up Plan;
- Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey;
- Initiation and Engagement of Alcohol and Other Drug Dependence Treatment: (a) Initiation, (b) Engagement;
- Hospital-Wide All-Cause Unplanned Readmission Measure (HWR) or Plan All-Cause Readmission;
- Falls: Screening for Fall Risk;
- Three-Item Care Transition Measure (CTM-3); and
- Optimal Diabetes Care.

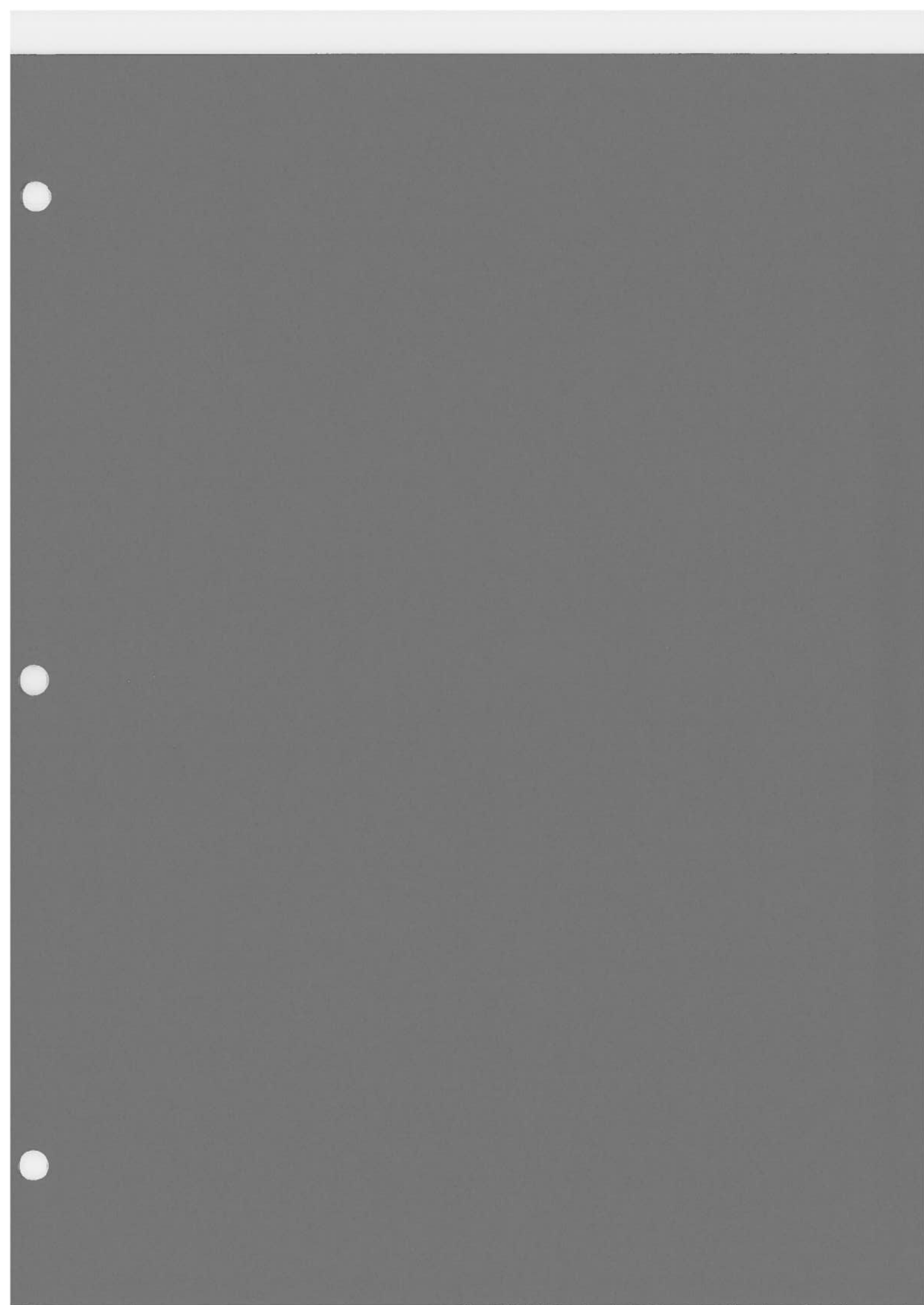
Additionally, the NCQA MAP Dual Eligible Workgroup suggested another measure set for Medicare-Medicaid enrollee programs, the Medical Home System Survey, but states monitoring the quality of provider networks serving as health homes would meet the intent of this recommendation.

Data use agreements should explicitly name health home providers as downstream users.

Conclusion

ABOUT THE INTEGRATED CARE RESOURCE CENTER

The ***Integrated Care Resource Center*** is a national initiative of the Centers for Medicare & Medicaid Services to help states improve the quality and cost-effectiveness of care for Medicaid's high-need, high-cost beneficiaries. The state technical assistance activities provided within the ***Integrated Care Resource Center*** are coordinated by Mathematica Policy Research and the Center for Health Care Strategies. For more information, visit www.integratedcareresourcecenter.com.



Implications of Health Homes for NCQA Health Plan Accreditation

State Medicaid programs across the country are advancing new health home programs for eligible beneficiaries, as authorized under Section 2703 of the Affordable Care Act. In some states, these initiatives are being designed for implementation within managed care delivery systems, with varying roles for Medicaid health plans in the delivery and management of health home services. Depending on how states structure their health home models, health plans may have responsibility for directly providing health home services; however, a more common approach to date has been for states to define non-health plan entities as health home providers (such as community mental health centers, primary care providers, or consortia of community-based providers). In this latter case, when the state designates primary care or other community-based providers to deliver health home services, the health plan may still be accountable for the management and oversight of health home services according to National Committee for Quality Assurance (NCQA) accreditation standards. This technical assistance tool, which was developed by the *Integrated Care Resource Center* (ICRC) and reviewed by NCQA, seeks to provide guidance to “health home states” and their health plan partners on these issues related to NCQA accreditation.

IN BRIEF: Many state Medicaid programs are pursuing the new state plan option to create health homes for eligible beneficiaries. Some states are developing health homes within a managed care model, with varying roles for health plans in the management and delivery of health home services.

This technical assistance tool from the *Integrated Care Resource Center* provides guidance on considerations related to National Committee for Quality Assurance (NCQA) health plan accreditation, particularly when non-health plan entities are designated as health home providers and health home services are provided outside of the health plans. NCQA reviewed and confirmed the considerations outlined in this document.

NCQA Standards at Issue

The specific NCQA health plan accreditation standards at issue include complex case management (QI 7) and disease management (QI 8) requirements, as well as the NCQA standard for delegation and oversight when these activities are performed by providers outside of the health plan (QI 12).^{1,2} Scoring for QI 7 and QI 8 involve the elements listed in Table 1, which include case reviews for selected elements. QI 12 requirements vary depending on whether the “delegated” provider is NCQA-recognized. These requirements are summarized in Table 2. In all cases except where state-approved health home providers are also NCQA-recognized Patient-Centered Medical Homes (PCMHs), the third column of the table (“Delegation to Practice Not Recognized by NCQA”) is most relevant to the health home discussion.

Requirements for Plans Delegating Health Home Services to Non-NCQA Recognized Providers

In reviewing this document, NCQA has confirmed the following requirements for health plan accreditation when health home services are provided by non-NCQA recognized providers:

- **Written delegation agreements are not required** provided that the state has approved the delegated entity as a health home provider in accordance with state-documented standards for health home service delivery,

Model	Potential for Duplication	Options for Addressing Duplication	Payment Options
OPTION 3: Health home operated in partnership between MCE and health home provider; the MCE does <i>not</i> already provide care management services that are consistent with the new health home services.	No duplication because the MCE is not providing care management services that are sufficiently robust to qualify as health home services.	<p>MCE must demonstrate that: (1) its current care management services do not overlap with health home services provided by the MCE or its health home partners; and (2) it is enhancing its care management services to be sufficiently robust to qualify as health home services.</p> <p>Health home services can be claimed at the enhanced 90 percent federal match rate for the first eight quarters. The State's actuary must identify the portion of the capitation payment associated with new health home services.</p>	Same payment alternatives as Option 2 above.
OPTION 4: Health home operated solely by the MCE; and the MCE <i>is already</i> providing care management services that are consistent with the new health home services.	Same as Option 2.	Same as Option 2.	State pays MCE directly.
OPTION 5: Health home operated solely by the MCE; the MCE <i>does not</i> already provide care management services that are consistent with the new health home services.	Same as Option 3.	Same as Option 3.	State pays MCE directly.
OPTION 6: MCE is the health home provider not only for its enrolled members but for Medicaid beneficiaries remaining in FFS but enrolled in health homes.	For FFS health home enrollees, there is no duplication as the beneficiary will continue to receive services via FFS.	N/A	State pays MCE directly. The MCE would receive only the health home payment for FFS beneficiaries, not the full capitation rate.

Health Home Considerations for a Medicaid Managed Care Delivery System: Avoiding Duplication of Services and Payments

Since Medicaid cannot pay twice for the same service for the same beneficiary, this technical assistance resource presents options for avoiding duplication of health home services and payments when managed care entities (MCEs) play a role in service delivery. The MCE can be either a comprehensive or specialized managed care organization (MCO) or primary care case management (PCCM) entity. The chart on the following pages describes different scenarios for how the health home can be situated within the managed care delivery system, including:

1. Health home operated outside the MCE;
2. Health home operated in partnership between MCE and health home provider, and MCE is already providing care management services;
3. Health home operated in partnership between MCE and health home provider, and MCE does not already provide care management services;
4. Health home operated solely by the MCE and MCE is already providing care management services;
5. Health home operated solely by the MCE, and MCE does not already provide care management services; and
6. MCE is health home provider not only for its enrolled members but also for Medicaid beneficiaries remaining in fee-for-service (FFS).

For each scenario, options are presented for addressing potential duplication of services and payments across the array of partners involved in health home service delivery. In summary:

- If the MCE's existing care management services do not duplicate services to be provided by health homes, the State can leave the MCE's capitation rate and contract requirements intact. The State will need to verify and demonstrate as part of the state plan amendment submission that the health home services do not duplicate existing care management services.

IN BRIEF: As states consider strategies to incorporate health homes into existing Medicaid managed care delivery systems, they must develop financing mechanisms to avoid duplication of services and payment. This technical assistance resource outlines options for states to develop health home approaches that complement but do not replicate services and reimbursement within existing managed care delivery arrangements.

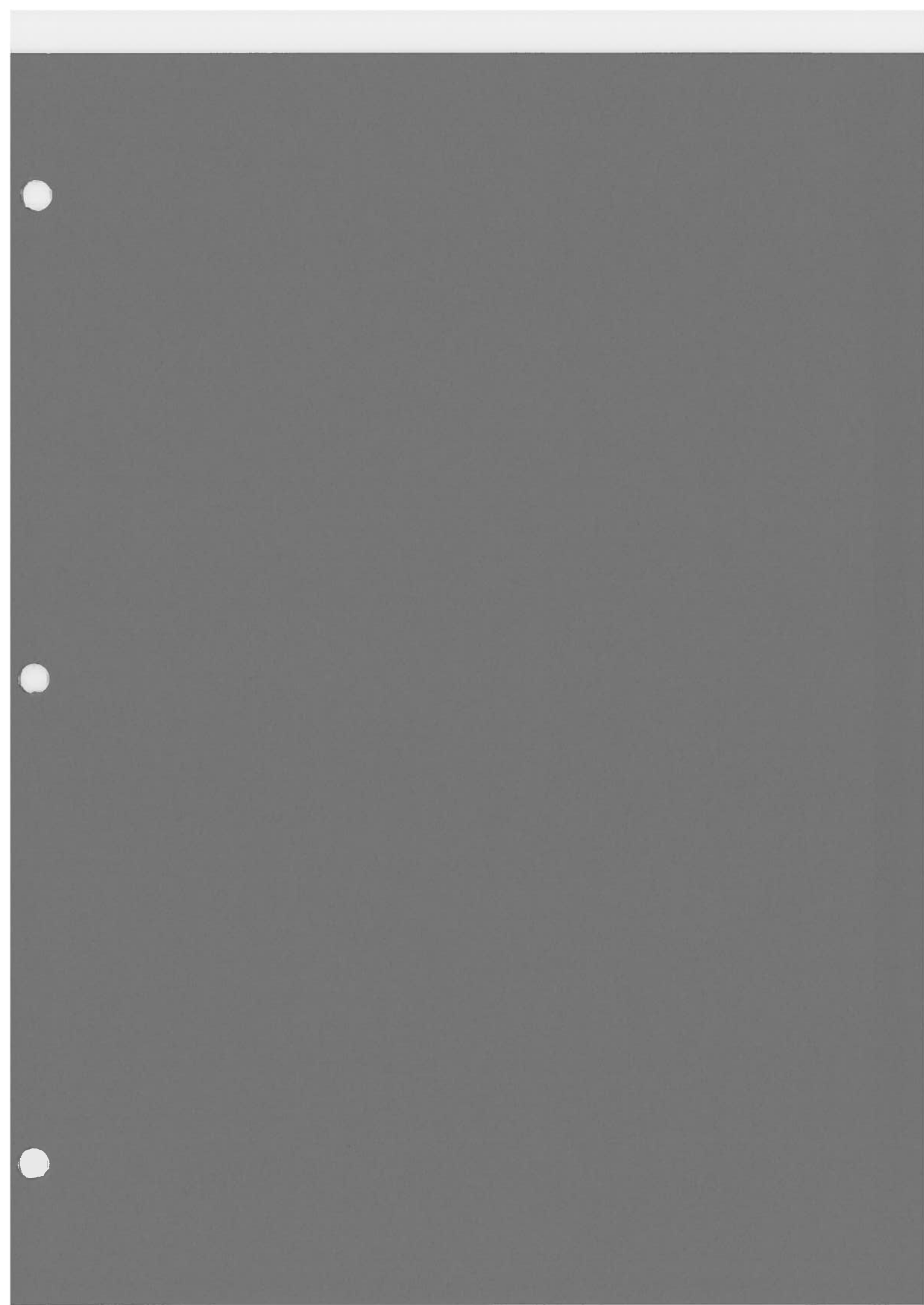
- If the MCE's existing care management services overlap with some or all health home services, the State can either identify the component of the MCE's existing capitation payment associated with duplicative health home services and reduce the capitation payment accordingly, or impose additional "in lieu of" contract requirements so that the MCE must perform additional non-duplicative services.
- If the MCE provides the health home services, the State will make a health home payment to the MCE for its enrolled members and the State can claim the enhanced 90 percent federal match rate for health home services for enrolled members. The MCE's original capitation rate for members not enrolled for health home services remains intact.
- If the MCE does not provide the health home services, the State will either: (a) remove funds from the MCE's capitation rate that previously supported any services that might overlap with health home services (e.g., care management); or (b) impose new contract requirements upon the MCE to provide non-overlapping services in lieu of the care management services previously provided by the MCE. The MCE's original capitation rate for members not enrolled for health home services remains intact.

- States should consider including health plans in the planning phase of their health home approach and allowing the plans to provide input on health home provider standards and/or selection. This may allow the plans to use this process to fulfill the capabilities assessment as required in QI 12. Additionally, as the State moves forward with the health home model, the State may want to include its health plans in health home quality oversight and monitoring, which also may provide evidence of the annual file audit and assessment requirements.
- If a State is considering using its health plans as part of the team of health home providers (e.g., the health plans will be involved in delivery of health home services), the State should consider what level of complex case management and disease management activities need to occur at the plan level to maintain their current NCQA status and may want to consider only providing additional activities included in the health home model at the practice level.

Table 1: Required Elements of NCQA Health Plan Standards QI 7 and QI 8

QI 7: COMPLEX CASE MANAGEMENT
Element A: Population Assessment Element B: Identifying Members for Case Management Element C: Access to Case Management Element D: Case Management Systems Element E: Case Management Process Element F: Initial Assessment* Element G: Case Management—Ongoing Maintenance* Element H: Satisfaction With Case Management Element I: Measuring Effectiveness Element J: Action and Re-measurement
QI 8: DISEASE MANAGEMENT
Element A: Identifying Chronic Conditions Element B: Program Content Element C: Identifying Members for DM Programs Element D: Frequency of Member Identification Element E: Providing Members With Information Element F: Interventions Based on Assessment Element G: Eligible Member Active Participation Element H: Informing and Educating Practitioners Element I: Integrating Member Information Element J: Satisfaction With Disease Management Element K: Measuring Effectiveness

* Scoring involves case reviews.





[Return to previous page](#)

[Home \(1\)](#) > [Medicaid \(/Medicaid-CHIP-Program-Information/Medicaid-and-CHIP-Program-Information.html\)](#) > [By-Topic \(/Medicaid-CHIP-Program-Information/By-Topics/By-Topic.html\)](#) > [Long Term Services and Support \(/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Long-Term-Services-and-Support.html\)](#) > [Integrating Care](#) > Health Homes

Health Homes

The Affordable Care Act of 2010, Section 2703, created an optional Medicaid State Plan benefit for states to establish Health Homes to coordinate care for people with Medicaid who have chronic conditions by adding Section 1945 of the Social Security Act. CMS expects states health home providers to operate under a "whole-person" philosophy. Health Homes providers will integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person.

Who Is Eligible for a Health Home?

Health Homes are for people with Medicaid who:

- Have 2 or more chronic conditions
- Have one chronic condition and are at risk for a second
- Have one serious and persistent mental health condition

Chronic conditions listed in the statute include mental health, substance abuse, asthma, diabetes, heart disease and being overweight. Additional chronic conditions, such as HIV/AIDS, may be considered by CMS for approval.

- States can target health home services geographically
- States can not exclude people with both Medicaid and Medicare from health home services

Health Home Services

- Comprehensive care management
- Care coordination
- Health promotion
- Comprehensive transitional care/follow-up
- Patient & family support
- Referral to community & social support services

Health Home Providers

States have flexibility to determine eligible health home providers. Health home providers can be:

- A designated provider: May be a physician, clinical/group practice, rural health clinic, community health center, community mental health center, home health agency, pediatrician, OB/GYN, or other provider.
- A team of health professionals: May include physicians, nurse care coordinators, nutritionists, social workers, behavioral health professionals, and can be free-standing, virtual, hospital-based, or a community mental health center.
- A health team: Must include medical specialists, nurses, pharmacists, nutritionists, dieticians, social workers, behavioral health providers, chiropractics, licensed complementary and alternative practitioners.

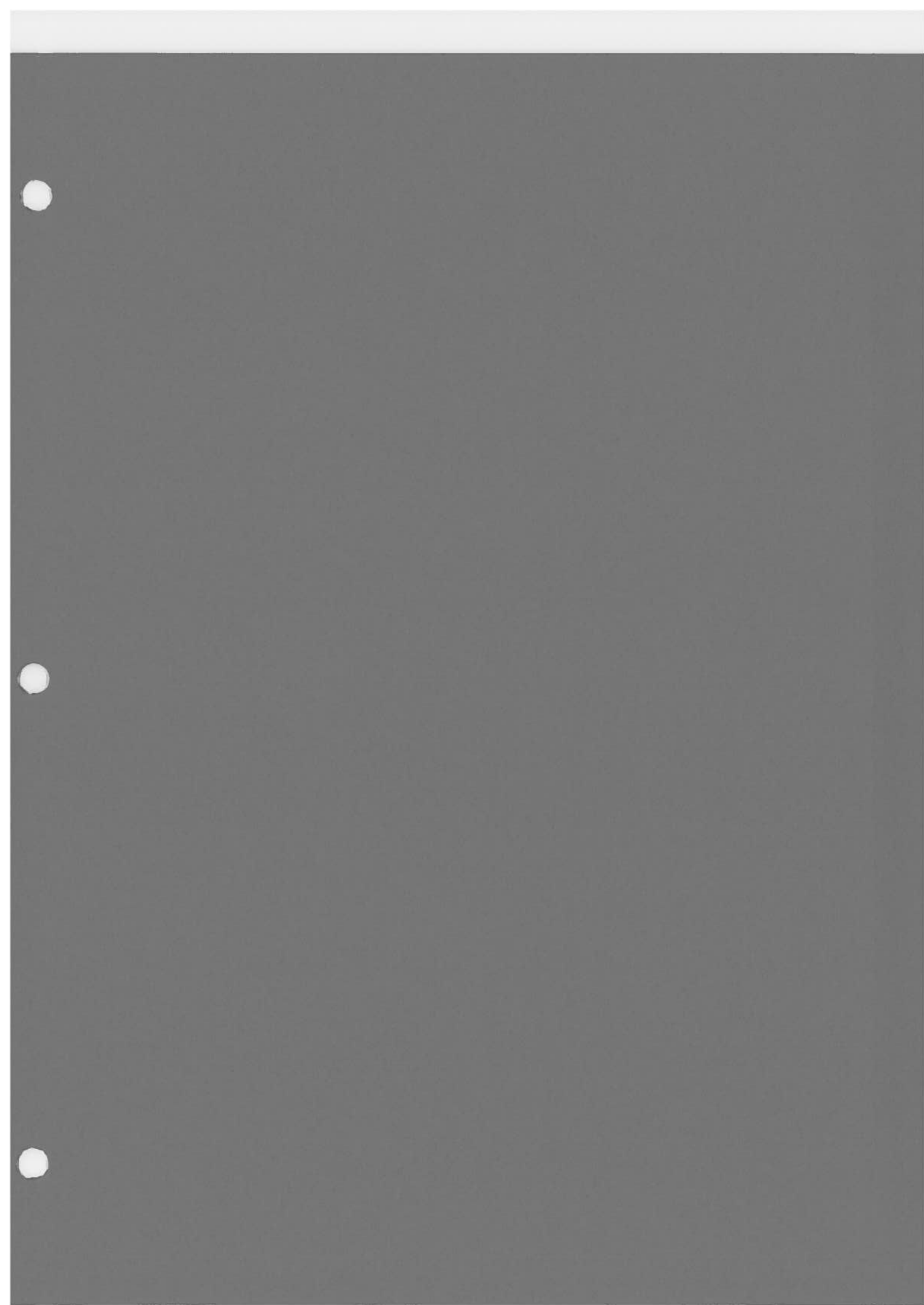
Reporting Requirements

Related Resources

- [Policy Guidance-Health Homes - 11/2010](#)
(<http://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD10024.pdf>)
- [SPA Template & Informational Bulletin - 12/2010](#)
(<http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-12-22-10.pdf>)
- [Social Security Sec. 1945](#)
(http://www.ssa.gov/OP_Home/ssact/title19/1945.htm)
- [Submit a Health Home State Plan Amendment](#)
(<http://trpharma.com/CMSDAT/Account.aspx/Login>)

Technical Assistance

- [Health Home Information Resource Center \(/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Health-Home-Information-Resource-Center.html\)](#)



What Would Strengthen Medicaid Long-Term Services and Supports (LTSS)?

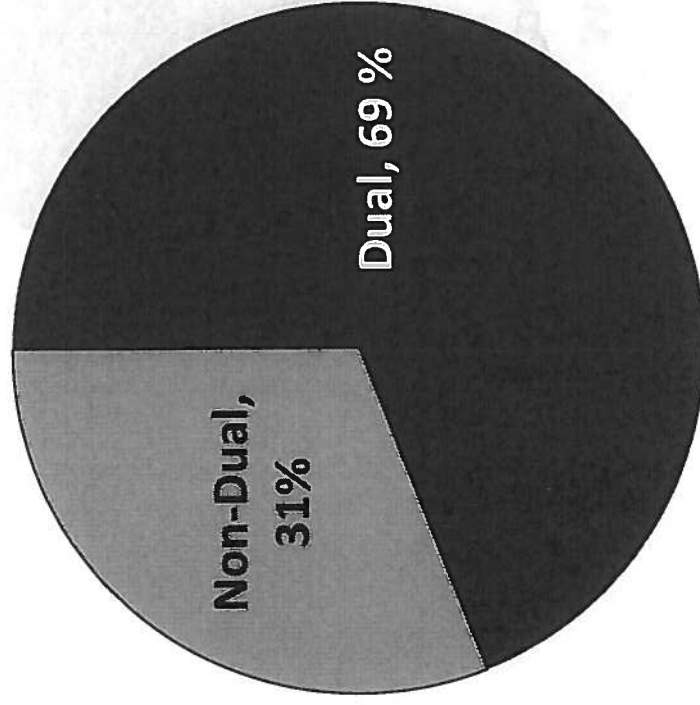
Federal Commission on Long-Term Care Public Hearing
Thursday, August 1, 2013

Diane Rowland, Sc.D.
Executive Vice President, Kaiser Family Foundation
Executive Director, Kaiser Commission on Medicaid and the Uninsured

Figure 2

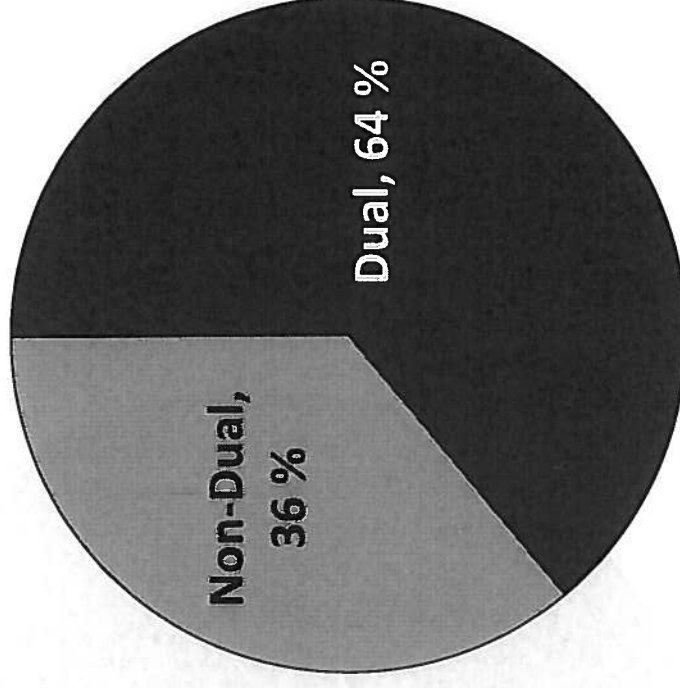
Distribution of Medicaid Beneficiaries Who Use LTSS, by Dual Eligibility Status, 2010

Enrollment



Total = 3.8 million

Expenditures

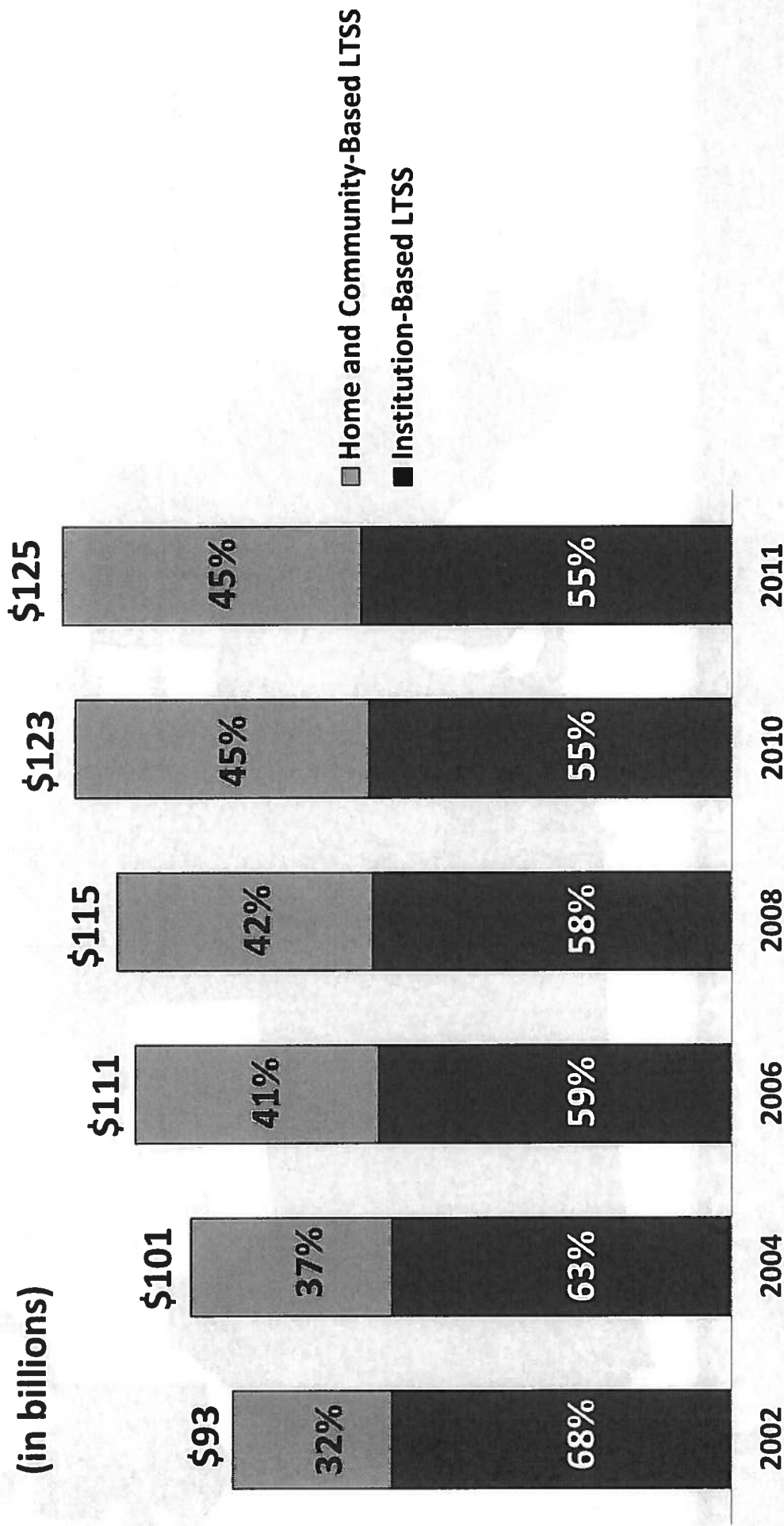


Total = \$159 billion

SOURCE: KCMU and Urban Institute estimates based on data from FY 2010 MSIS. Because 2010 data was unavailable, 2009 data was used for Colorado, Idaho, Missouri, and West Virginia.

Figure 4

Growth in Medicaid LTSS Expenditures, 2002 - 2011

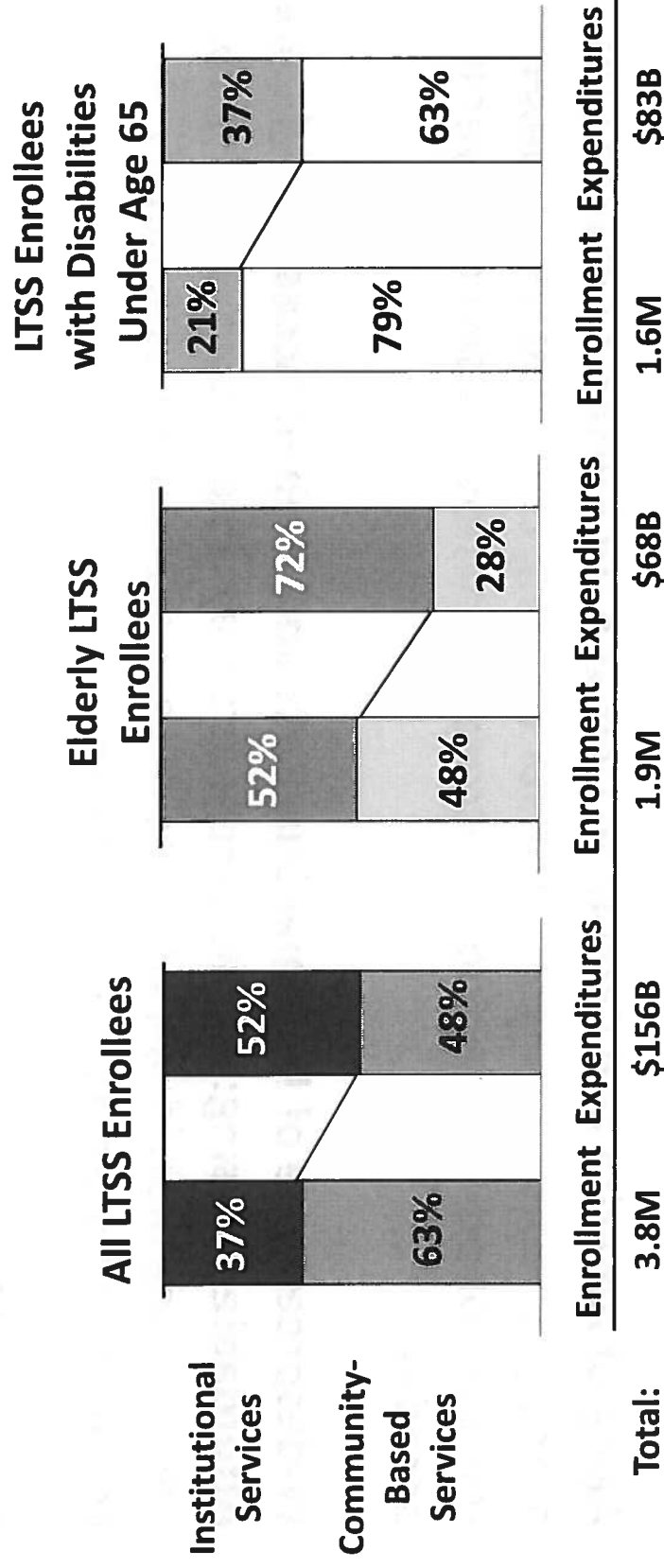


NOTE: Home and community-based care includes state plan home health, state plan personal care services and § 1915(c) HCBS waivers. Institutional care includes intermediate care facilities for individuals with intellectual/developmental disabilities, nursing facilities, and mental health facilities.

SOURCE: KCMU and Urban Institute analysis of CMS-64 data.

Figure 6

Distribution of Enrollment and Spending Among Medicaid LTSS Beneficiaries, by Population, 2009



NOTE: Note: Individuals who used both institutional and community-based services in the same year are classified as using institutional services in these tables.

SOURCE: KCMU and Urban Institute estimates based on data from FY 2009 MSIS. Because 2009 data was unavailable, 2008 data was used for Pennsylvania, Utah, and Wisconsin.

Figure 8

States' Participation in Six Key Medicaid LTSS Options Provided or Enhanced by the Affordable Care Act

46

29

26

18

14

10

Money Follows the Person Demonstration	Health Home State Plan Option	Financial Alignment Demos for Dually Eligible Beneficiaries	Balancing Incentive Program	HCBS State Plan Option	Community First Choice State Plan Option
--	-------------------------------	---	-----------------------------	------------------------	--

NOTE: Number of states that are participating, used to participate, or have plans to participate in FY 2013 or FY 2014 as of July 2013.

SOURCE: M. O'Malley Watts, M. Musumeci, and E. Reaves, *How is the Affordable Care Act Leading to Changes in Medicaid Long-Term Services and Supports (LTSS) Today? State Adoption of Six LTSS Options*, The Henry J. Kaiser Family Foundation, April 2013, available at: <http://www.kff.org/medicaid/issue-brief/how-is-the-affordable-care-act-leading-to-changes-in-medicare-long-term-services-and-supports-ltss-today-state-adoption-of-six-ltss-options/>; updated July 2013.

Don, Age 41, Michigan



Don was born with developmental disabilities. With help of his legal guardian, Don qualified for self-directed Medicaid in-home services; he enjoys having the freedom to allocate his Medicaid dollars for approved services. Don uses most of these dollars to hire his own caregivers. Having caregivers who he trusts greatly improves Don's quality of life. He wishes to remain in the community and live independently.



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RESEARCH BRIEF

**Comparative Effectiveness
of Care Coordination
for Adults with Disabilities**

July 2011

Melanie Au, Samuel Simon, Arnold Chen,
Debra Lipson, Gilbert Gimm, and Eugene Rich

MATHEMATICA
Policy Research

Comparative Effectiveness of Care Coordination for Adults with Disabilities

by Melanie Au, Samuel Simon, Arnold Chen, Debra Lipson, Gilbert Gimm, and Eugene Rich

ISSUE AT A GLANCE

The notion that care coordination can improve outcomes for people with disabilities or complex health needs has existed for decades.¹ Beginning with On Lok and the National Long Term Care Demonstration,² policymakers and researchers have sought to establish a strong basis for this belief. To some extent, their efforts have paid off. There is substantial evidence that care coordination can, under certain circumstances, improve outcomes for people with chronic conditions (Peikes et al. 2009; Boulton et al. 2009). However, it has been difficult to replicate or scale up approaches that have shown promise in early, small studies (Boulton et al. 2009; Lipson and Au 2010). Moreover, several factors have stymied attempts to identify a generalizable program design with predictable benefits, including the complexity of such programs, differences in targeted populations, and variation in program organization, staffing, and context. The findings from systematic reviews of the literature on care coordination for adults with disabilities have been mixed (Ziguras and Stuart 2000; Marshall 2010; Liebel et al. 2009), and there is little detail on common, key elements.³

Policymakers and practitioners continue to gravitate toward care coordination, placing it at the center of new models of care such as accountable care organizations and medical homes. At the heart of these activities is a belief that coordination works, but pinning down what “it” is has been difficult.

In response to this trend, Mathematica has developed a conceptual framework to describe (1) the basic elements of care coordination and how they might vary according to the type or severity of a disability(ies), (2) the relationship to health and supportive services, and (3) expected results and outcomes. We then used this framework to conduct a systematic review of the literature on care coordination for people with disabilities, focusing on information about key program elements.

The review revealed major weaknesses in the literature, the most prominent being the absence of information on many basic elements of care coordination—even in rigorous studies. Going forward, our framework should help researchers identify a common set of elements to use in all descriptions and evaluations of care coordination programs. Policymakers, practitioners, and program developers can use the framework to form a checklist as they consider how to structure and operate care coordination programs to maximize the benefits for people with disabilities.

¹We use the term “care coordination,” although such programs are also known as case management and disease management programs.

²On Lok was the precursor to PACE (the Program for All-Inclusive Care for the Elderly), and the National Long Term Care Demonstration is also known as “Channeling.”

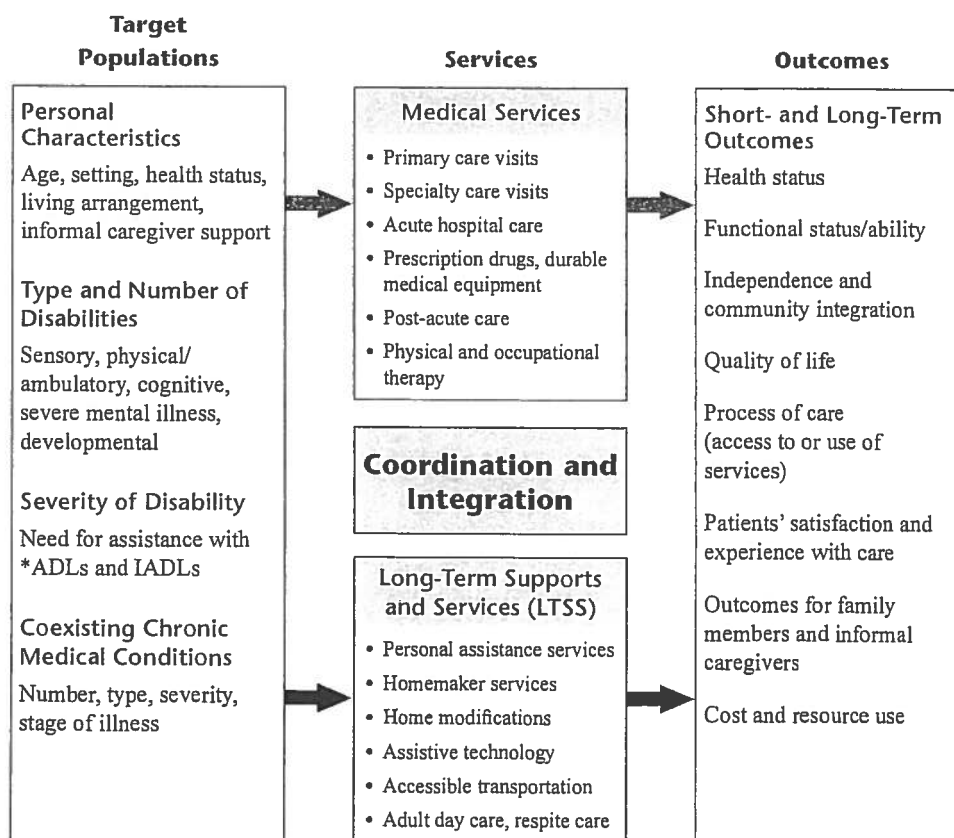
³A list of the reviews examined is available at http://www.mathematica-mpr.com/chce/review_au_0711.asp.

Developing a Conceptual Framework

Given the importance of a robust intervention typology that would be relevant to real world decision makers, we developed a conceptual framework, presented in three figures, that illustrates how care coordination programs work. Figure 1 illustrates the complexity of effective care coordination. A range of patient characteristics and circumstances (left side in the figure) determine patient needs for medical services and long term supports (middle). This mix of services, which can differ even for patients with similar disabilities, affects a number of outcomes (right side) in varying ways. Care coordination (in the center) is essential to matching the appropriate combination of services to the right patients and coordinating the delivery of those services to improve outcomes. The dimensions and features of different care coordination programs are presented in Figures 2 and 3. While this framework does not capture every type of care coordination model, nor specify every discrete pathway through which care coordination may affect outcomes, it highlights the importance of specifying (1) the characteristics of the population(s) served (Figure 1), (2) the types of services coordinated in the program (Figure 1), and (3) the dimensions and features of different care coordination programs (Figures 2 and 3).

Adults with disabilities are like all other people in their need for basic health care and their desire to be fully included in society. But their health and social care needs differ from the

Figure 1. General Framework of Populations, Services, and Outcomes



*ADLs = Activities of daily living ; IADLs=Instrumental ADLs

general populations' due to impairments in physical, cognitive, developmental, or sensory ability. Even individuals with similar disabling conditions can have very different needs and very different preferences for the type and intensity of services or supports they receive. For example, adults with physical disabilities may need help with all or just a few activities of daily living (ADLs), such as eating, bathing, dressing, or toileting. Adults with cognitive or developmental disability may need help with some or all instrumental activities of daily living (IADLs), such as managing household finances, getting outside the home, and shopping for groceries. Some adults with serious mental illness can follow treatment plans; others may need considerable support to do so. Adults with multiple disabilities and/or co-existing medical conditions may have more functional limitations, so they may have an even greater need for diverse services and care coordination. Anyone seeking to determine the comparative effectiveness of services for persons with disabilities, therefore, must avoid a "one-size-fits-all" approach.

There are many ways to classify the range of outcomes that matter most to people with disabilities. Our conceptual framework shows the range of outcomes commonly examined in the literature across eight domains: (1) health status; (2) functional status or ability; (3) independence and community integration; (4) quality of life; (5) process of care measures (including timely access to and use of needed services); (6) patient satisfaction and experience with care; (7) family and informal caregiver health and well-being; and (8) cost and resource utilization. Depending on their perspective and circumstances, individuals will value some of these outcomes more than others. For example, community-dwelling adults with disabilities may consider quality of life and integration in society to be the most important outcomes. For purchasers of services, cost and process of care outcomes may be most important. Because our systematic review of evidence on care coordination seeks to provide the information needed by different types of decision makers, our conceptual framework acknowledges the range of outcomes of interest to them.

Services to be coordinated. Within our conceptual framework (Figure 1), the outcomes of care desired by persons with disabilities are mediated by their receipt of medical care, which is intended to treat or prevent specific health conditions, and long-term supports and services (LTSS), which seek to facilitate functioning. Care coordination plays a key role in determining timely access to needed services. Meeting the needs of adults with different types of disabilities can be particularly challenging because they may require a variety of medical services and LTSS to maintain health and functioning. Yet the providers and systems that deliver these two types of services operate very differently and may not interact with one another (Leutz 2005). These realities increase the potential value of care coordination and also make its successful implementation challenging.

The medical services required by community-dwelling adults with disabilities fall along a continuum from general medical care, such as what might be provided during a physician office visit, to home hospice care during the waning days of life. Between these points, a person may receive outpatient services from a range of physician specialists; acute care inpatient services in hospitals; and an array of technological services (diagnostic tests and imaging) and therapies delivered in hospitals, physicians' offices, or specialized outpatient facilities (imaging centers, surgical centers, and rehabilitation centers, for example).

LTSS, by contrast, are designed to help individuals with disabilities maintain independence and functional status, and overcome limitations with daily activities. Examples include personal assistance services, assistive technology, home modifications, home care aides,

and respite programs that support informal and family caregivers. Other services, such as accessible transportation and adult day care, facilitate social participation in the community.

Features of care coordination. Care coordination is situated in the middle of the framework (Figure 1). The 2009 report of the Federal Coordinating Council for Comparative Effectiveness Research calls it “critical” in helping persons with disabilities “live independently in their communities with added years of quality life” (FCCER 2009). Yet in the medical, health services research, and disability literatures, the term “care coordination” does not have a single consistent meaning. A 2007 Agency for Healthcare Research and Quality (AHRQ) systematic review (which focused more on coordinating medical services than on addressing the specific needs of individuals with disabilities) defined care coordination as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services”; it went on to assert that “organizing care involves the marshalling of personnel and other resources needed to carry out all required care activities, and is often managed by the exchange of information among participants responsible for different aspects of care” (McDonald et al. 2007). As this AHRQ review notes, some models of care coordination focus mainly on the integration of medical services. Others, described more fully below, help populations with disabilities by coordinating different types of LTSS. Still others seek to integrate both medical care and LTSS for persons with disabilities. Our conceptual framework builds on the AHRQ report while emphasizing the potential need to integrate relevant medical services as well as social supports across multiple providers and settings in order to improve outcomes for community-dwelling adults with disabilities.

Figure 1 illustrates how various care coordination programs might differ depending on the target population, scope of services coordinated, and outcomes of interest. Figure 2 illustrates how, within these programs, specific elements and program features that affect the implementation and outcomes of care coordination may vary substantially. For any specific population targeted for care coordination, the programs may vary along several dimensions, including which services are to be coordinated, who coordinates or manages care (and whether they are part of an interdisciplinary team), how frequently and over what period

Figure 2. Dimensions and Features of Care Coordination Models

Phone call, Checklist	Needs Assessment	Comprehensive assessment with home visit
Non-clinical	Training and Experience	Clinical doctorate
Isolated case manager	Team Composition	Integrated multidisciplinary
Limited HCBS*	Scope of Services	All medical and HCBS
Occasional phone call	Intensity of Effort	Frequent home visits
Hospital home transition	Duration of Effort	Long-term and continuous relationship
Referrals	Information Exchange	Shared secure electronic record
None or limited	Patient/Family/Caregiver Engagement	Shared decisions and periodic meetings

*Home and community-based services

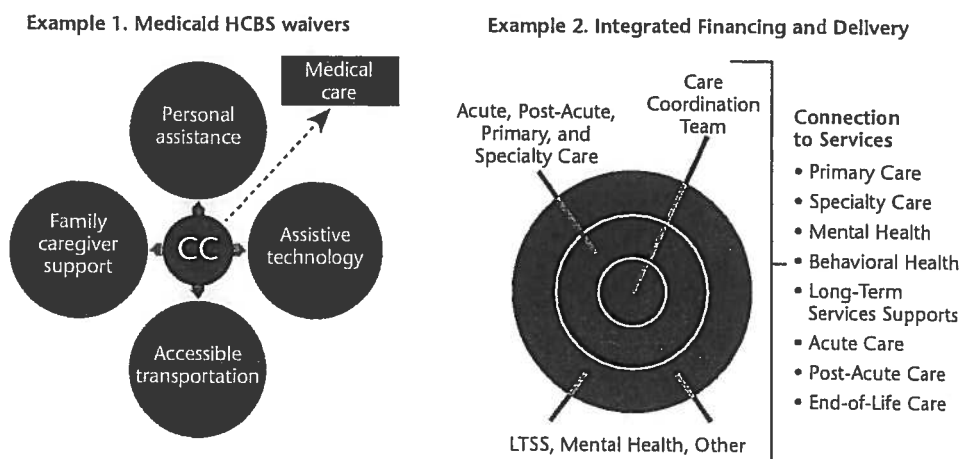
of time services are coordinated, and the extent and quality of information exchanged between providers and care coordinators, as well as the involvement of patients, family members, and other informal caregivers in decision-making.

Influence of organizational setting and financing context. The various organizational settings and financing contexts for services are potentially important mediating factors in determining how effectively care is coordinated. Indeed, the way in which medical, LTSS, and other services are organized and financed may be critical to achieving desired outcomes, by influencing the ease of service coordination and the number and quality of the services received (Figure 3).

Organizational settings for delivering services to adults with disabilities vary widely. They range from several individual health professionals operating independently in different organizations and agencies, to integrated systems in which interdisciplinary teams work closely together at the same site to assure that all needed care is provided. The number and type of health care organizations involved in an individual's care can determine the number and type of services recommended, as well as the ease or difficulty of connecting persons with disability to needed services. The organizational setting for care coordination can influence the number and type of professionals involved, as well as the resources available for needs assessment (and thus its scope and sophistication). It can also influence which professionals serve as case managers (physician, nurse, or social worker, for example) and whether care is coordinated by a team or an individual.

The financing of health care and LTSS under public or private insurance has a strong relationship with access to services, especially for adults with disabilities, since it influences both the timing and the scope of services available. For example, adults who qualify for Medicare can get coverage for medical services, prescription drugs, and devices deemed "reasonable and necessary for the diagnosis and treatment" of an illness or injury. But Medicare does not cover long-term home and community-based services (HCBS), and it provides limited coverage for services aimed at enhancing mobility, self-care, and independence, such as physical therapy and assistive technology (Field and Jette 2007). Depending on their income and assets, disabled individuals may or may not be eligible for Medicaid or other programs that cover benefits not included under Medicare, or that subsidize Medicare monthly premiums, deductibles, and copayments. If individuals must pay such costs themselves, they may not get all the services needed to assure good outcomes. If they qualify for two or more programs as "dual-eligibles" (for example, Medicare and private disability insurance, or Medicare and Medicaid), they may still experience problems in coordinating benefits to ensure timely access to services.

Various programs using available organizational and financing systems have emerged over the years to address the coordination (and provision) of medical and social services to adults with disability. For example, nearly every state Medicaid agency finances various forms of case management in HCBS waiver programs (Figure 3, example 1). In this model, the case manager exerts direct control over access to HCBS services and financing, but uses more modest "linking and referral" (shown as a dotted line) mechanisms to encourage appropriate medical care by physicians or other health professionals. At the other end of the spectrum are fully integrated models for the organization and financing of both care coordination and services (Figure 3, example 2). This model is exemplified by the Program of All-Inclusive Care for the Elderly (PACE), as well as by some state programs operating under federal waivers, which combine Medicaid and Medicare financing to pay managed care organizations

Figure 3. Organization and Financing of Care Coordination

at capitated rates for providing all medical and long-term care services for persons with disability. In between, other models of care coordination function in different organizational and financing contexts, and therefore use different approaches to coordinate subsets of benefits and services across financing sources and providers and agencies.

Implications for review of evidence on care coordination. The role of both the organization and financing of services in determining the outcomes of services and care coordination for adults with disabilities has implications for our systematic review of the literature. In assessing the relative effectiveness of care coordination approaches, we sought to compare those that operate under similar organizational and financing models in order to reduce the chance that outcomes were influenced by organizational structure, benefits and services covered under participants' financing sources, and reimbursement incentives in financing programs. Accordingly we analyzed care coordination effectiveness by organization and financing models: the categories were Medicaid Fee for Service (FFS), Medicaid Consumer Directed Cash Benefit, Integrated Medicaid and Medicare, Medicare capitation, private health care organizations, Veterans Affairs' programs, private foundations, and mixed-funding sources.

With respect to the relationship of specific features of care coordination to various outcomes, an earlier review of reviews revealed mixed findings. Despite widespread endorsement of care coordination as a strategy for improving the quality of care, increasing patient satisfaction, lowering costs, and improving health status, our "review of reviews" of programs for persons with disabilities showed that care coordination had limited effects. We also found very little information on the potentially important features of care coordination programs, even features that previous evaluations of care coordination deemed important [for example, greater in-person contact and more targeting to higher-risk patients (Peikes et al. 2009)]. Indeed, many of the systematic reviews we identified recommended that future studies be more specific about a number of features, including the study population, how the population was targeted, the scope of needs assessment, the professional training and qualifications of care coordinators, the integration of care coordinators with service providers, and the intensity (amount, frequency, and length) of contact between care coordinators and patients, and their caregivers. Our systematic review of original literature therefore focused specifically on evidence for how these key dimensions of care coordination influence program effectiveness.

What Did We Find?

We searched the published and the “grey” literature from 2000 to 2010 for primary studies on the effectiveness of care coordination programs for adults with disabilities. This review focused on care coordination programs aimed at optimizing independent living for community-dwelling adults with disabilities. We therefore excluded models used in institutions as well as broad-based interventions in which it is difficult to separate care coordination from other intervention components (for example, PACE). (See pages 14 to 15 for a description of our methods.)

Although the body of literature on care coordination is extensive, only a few evaluation studies address what works for whom. Specifically, our search criteria identified a total of 9,866 articles (after removing duplicates), but only 46 of those were judged to be evaluations that met our inclusion criteria. We excluded 9,289 articles during a title-level review and an additional 456 during an abstract-level review based on the criteria described in the methodology, because the studies were off-topic, did not include people with disabilities, did not include a community-dwelling population, were only about children, did not include any care coordination services, did not include outcomes of interest, or were not implemented in the U.S.⁴ We used a number of search terms to sufficiently capture our disability categories. However, the amount of articles excluded at title-level review suggests that additional fine-tuning of search terms may have reduced the number of articles requiring review.

We divided the 46 articles into groups based on type of disability and funding source. Seventeen articles addressed care coordination for people with severe and persistent mental illness (SPMI), 9 addressed individuals with cognitive impairment, 3 addressed people with physical impairment, and 17 addressed populations with multiple disabling conditions (Table 1).⁵ No studies that examined care coordination for people with developmental/intellectual impairments or sensory impairments met our inclusion criteria. The most common funding sources cited in the 46 articles were private health care organizations (10), Veterans Affairs (VA) (9), and Integrated Medicaid and Medicare (7). Eight studies were supported by a mix of funding (for example, a combination of both foundation and private health care organization resources). No intervention we reviewed was funded through the other funding mechanisms we sought to examine: Medicaid FFS, Medicaid Consumer Directed Cash Benefit, and Medicare capitation.

Only 19 of the 46 studies relevant to our review were designed such that the findings had moderate or high internal validity. Table 2 shows the limited evidence we found for various types of disabilities. While a number of the 19 evaluations reported favorable impacts on outcomes, the state of the literature cannot support definitive conclusions about which program features will yield the best outcomes for people with particular disabilities. The problem is twofold: the programs served several distinctly different types of patients through a variety of organizational and financing mechanisms (Table 1); and the information on specific features of the programs was frequently incomplete or the features themselves

⁴Additional details on our methodology can be found in the full report, which can be requested by emailing chce@mathematica-mpr.com.

⁵The full report includes a variety of tables that present information on studies by type of disability addressed (SPMI, cognitive impairment, physical impairment, and multiple disabling conditions). In each section, an initial table presents descriptive information on the studies reviewed; a second table provides information on care coordination dimensions; and a third table presents information on findings. The report can be requested by emailing chce@mathematica-mpr.com.

Table 1. Summary of Review Articles by Population and Funding Categories

	Medicaid: Managed Care Organization	Integrated Medicaid and Medicare	Medicare FFS	Foundation/ NIH	Private Health Care Organization	Veterans Affairs	State Department of Health/ Mental Health	Mixed Funding	Other	Total
SPMI	—	—	—	4	3	4	2	4	—	17
Cognitive Impairment	—	—	—	1	5	1	—	1	1	9
Physical Impairment	—	2	—	1	—	0	—	—	—	3
Multiple Disabling Conditions	1	5	1	—	2	4	—	3	1	17
Total	1	7	1	6	10	9	2	8	2	46

were inadequately documented (Table 3). We sought to abstract key elements of care coordination from our conceptual framework (Figure 2): needs assessment, coordinator experience/background, team composition, scope of services, and intensity of coordination. As shown in Table 3, many of these dimensions are not consistently reported.

Our systematic review found that the current literature cannot support identification of consistent patterns of effectiveness and lacks detail needed to understand the importance of care coordination dimensions for adults with disabilities. However, for policymakers searching for lessons they might readily apply to their current circumstances, we highlight those programs where evidence suggests a meaningful impact on one of three outcomes of broad interest: (1) independent living, as measured by reduced hospital admissions and nursing home use, (2) health status, and (3) quality of life. For each disability category, we highlight specific features of the few programs that demonstrated impact on such outcomes.⁶

Adults with serious and persistent mental illness. For care coordination programs directed to adults with SPMI, only one in seven programs demonstrated an outcome relevant to improved independence, in this case reduction in psychiatric hospital admissions and hospital days. This initiative, focused on clients with co-occurring SPMI and substance use disorders, was financed through state-funded mental health services (Mangrum et al. 2006). The intervention was provided to 123 clients at three sites, all of which established a dual-diagnosis treatment team providing care coordination and access to a range of mental health and substance abuse services (psychiatric services, individual therapy, and specialized groups tailored to client issues). The sites varied in the extent to which they established broader community networks with ancillary service providers; several other care coordination program details are not reported (for example, approach to needs assessment, intensity of contact, type of outreach).

Table 2. Limited Evidence Base

Target Condition	Number of Studies	Internally Valid Studies
SPMI	17	7
Cognitive Impairment	9	3
Physical Impairment	3	0
Multiple Disabling Conditions	17	9
Total	46	19

⁶Other outcomes are presented in the full report, which can be requested by emailing chce@mathematica-mpr.com.

Table 3. Selected Dimensions of Care Coordination Described in Literature

Dimension	SPMI (N=7)	Cognitive Impairment (N=3)	Multiple Disabling Conditions (N=9)
Needs Assessment	2	2	1
Coordinator Experience or Background	5	2	9
Team Composition	3	2	6
Scope of Services	5	2	6
Intensity of Coordination	3	1	5

Although no other studies judged to have at least moderate internal validity reported program benefits on independence for adults with SPMI, two models of care coordination that address both medical and psychiatric care showed moderate evidence (albeit with small samples) for improved health status or quality of life. Both studies were in the VA health care system. One program involved a multidisciplinary team providing primary care in a dedicated clinic adjacent to mental health services; the evaluation demonstrated improved physical health status (SF 36 subscale) for 59 veterans served by the intervention (Druss et al. 2001). In this program, registered nurses provided patient education and were liaisons with mental health providers and case management service providers, while physicians served as liaisons to the psychiatry service. The other promising program, a multicomponent bipolar disorder medical care model, demonstrated improved health-related quality of life for 27 veterans with bipolar disorder and cardiovascular risk factors at higher risk for repeated admission to hospitals or nursing facilities than veterans receiving usual care (Kilbourne et al. 2008). The program included a self-management component, educational sessions, and care coordination by a registered nurse. However, in both these programs, some key details of the care coordination intervention (for example, needs assessment process and care coordination intensity) were not described.

Adults with cognitive impairment. We found no studies of moderate or high internal validity demonstrating that care coordination improved independence for adults with cognitive impairment. We did, however, identify one study of at least moderate internal validity that demonstrated benefits on health status. A multi-site evaluation by Vickery et al. (2006) of the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Program (funded and organized by a collaboration of three private health care organizations and three community agencies) demonstrated that a specific guideline-based dementia care management intervention for 238 patients achieved a relative improvement in health-related quality of life, as reported by patients. This program featured use of case management software to develop and prioritize a problem list and care recommendations that case managers reviewed with caregivers. The employment arrangements for the care coordinators varied in this program, with some working for community-based organizations and some for care delivery organizations.

Adults with physical impairments. We found few studies overall and no studies with at least moderate internal validity addressing the effectiveness of care coordination interventions for adults with physical impairments.

Adults with multiple disabling conditions. Our systematic review found only one study of moderate or high internal validity offering evidence that care coordination improved independence for adults with multiple disabling conditions. That evaluation, by JEN Associates (2008), found a significant reduction in the rate of nursing home entry for 635 participants in Senior Care Options, an integrated Medicare and Medicaid managed

care program offered to elderly Massachusetts Medicaid beneficiaries. Several different senior care organizations (SCOs) provide a complete benefit package that includes the full range of Medicaid and Medicare services for enrollees. Each SCO undertakes some aspects of care coordination, but several key details vary across these organizations. Consistent aspects include the breadth of the services coordinated (medical services, behavioral health, prescription drugs, and long-term support services) and the integration of the care coordination function with the organizations delivering services.

We found several studies of at least moderate internal validity that showed improvements in quality of life under care coordination programs operating in various organizational and financing settings. Claiborne (2006) described a care coordination program for stroke survivors supported by mixed funding sources. The intervention group ($n = 28$) showed significantly improved quality of life, decreased depressive symptoms, and increased adherence to self-care practices. In this program, social workers coordinated a wide range of medical and social services in a link-and-referral model. The study describes the needs assessment approach and intensity of the care coordination intervention. Marek et al. (2010) reported improved ADLs as well as a decrease in pain and other symptoms for 55 nursing home–eligible elders in the Aging in Place program of integrated Medicare and Medicaid financing. The care coordination was provided by specially trained nurses who operated in a fully integrated model, managing a broad range of medical and long-term services and supports. Comprehensive needs assessment and periodic home visits were also elements of this care coordination intervention.

The additional two programs with at least moderate evidence of health status benefits were directed at frail elderly military veterans. Cohen et al. (2002) reported that nearly 350 veterans experienced significant improvement in mental health after participating in a program of outpatient geriatric evaluation and care coordination. After comprehensive geriatric assessment, the interdisciplinary geriatrics team coordinated a broad range of services in a fully integrated model. The report did not provide details on the type and intensity of the outpatient aspect of care coordination. Chumbler et al. (2004) reported on 111 military veterans who received “tele-health” care coordination through telephone conversations with registered nurses or nurse practitioners. These care coordinators collected data for managing complex health needs (needs assessment not described in detail) and also provided education on self-management principles. No details are provided on the range of services coordinated or the linkage with the other providers of clinical or support services. The treatment group had significant improvements in IADLs as well as motor and cognitive functioning.

Areas of convergence across studies. Despite substantial heterogeneity of population needs and financing models for coordinating services observed across the literature, several broad areas of convergence were identified among studies with at least moderate internal validity and a focus on independence or health status. First, an integrated service delivery environment was a common feature among studies with positive findings linking care coordination and increased independence. Indeed, of the nine programs highlighted above, six occurred in the context of the VA health care system, in another integrated delivery system, or within a program of integrated financing of services. Thus, integration of payment and service delivery may facilitate successful care coordination practices compared with other approaches to organizing and financing of care. Related to integration of service delivery was the role of the care coordinator with other care providers. Where it was documented, the care coordinators’ role was closely integrated with other providers in several of the studies showing positive findings on independence and health status. In this way, the role of care liaison provided by

care coordinators shows promise to facilitate communication between providers and can effectively link individuals with disabilities with providers resulting in improved care outcomes. Unfortunately, these features cannot be readily disentangled from another common element of these highlighted care coordination programs, which is an organizational mechanism that integrates either the financing or the delivery of care (often both).

Implications

Care coordination for adults with disabilities is the archetype of the “complex intervention” that challenges traditional systematic review methodology (Shepperd et al. 2009). The variety of programs for diverse populations of adults with disabilities inevitably resulted in the inclusion of studies that looked at many different interventions in a range of distinct payment and organizational environments. Furthermore, to be useful to different types of decision makers, we reviewed studies that measured a diverse set of outcomes; as a result, the comparative effectiveness of interventions in producing specific outcomes cannot be measured quantitatively, which is typically done in traditional systematic reviews of a clinical intervention like a drug or medical procedure. A second challenge stems from our decision to include studies in our review even when they did not systematically describe potentially important aspects of the intervention. Given the limitations of the existing body of literature, we provide recommendations for future implementation and evaluation activities to provide policymakers and other stakeholders with better evidence about the effectiveness of care coordination for individuals with disabling conditions.

Implications for policy and practice. Given the scattered findings and small sample sizes in the studies we reviewed, the evidence remains limited regarding the relative effectiveness of different elements of care coordination for adults with disabilities.

For decision makers considering the implementation of care coordination interventions within integrated care delivery settings (like the VA health system) or integrated Medicare and Medicaid financing programs (like the SCOs in Massachusetts), there is some limited evidence. Our systematic review identified several examples of effective programs, though most of the program evaluations described above have limited sample size and often occurred in relatively unusual settings. For many, the contribution of key dimensions of the care coordination program to the outcomes was not carefully examined. Thus, even if one wanted to replicate an effective program in the same financial and organizational circumstances for the same kinds of patients with disability, one can have only limited confidence that the program will perform comparably if the model is even slightly changed.

Moreover, most community-dwelling adults with disabilities are not presently cared for in integrated delivery systems, nor are they enrolled in health plans that receive capitated financing. For decision makers seeking to address the care coordination needs of most patients receiving care in the current non-integrated, FFS system, evidence of effectiveness of any particular care coordination program is even sparser. Clearly, the programs evaluated vary dramatically in many elements that may be critical to success. To have sufficient information to scale up or otherwise replicate care coordination interventions, policymakers will need much more robust evidence addressing several key questions: What target population can most benefit from care coordination? Which organizational and financing mechanisms increase the likelihood that care coordination will be effective? How do variations in specific features of care coordination (for example, coordinator training, coordinator linkage to the delivery system, needs assessment approach, intensity of patient contacts) affect program effectiveness? Given the long-term costs

of care coordination programs for adults with disabilities, and the uncertainties associated with their effectiveness, implementing truly effective programs will require rigorous evaluations to answer these important questions reliably.

Yet policymakers and organizational leaders often find themselves obliged to implement a care coordination intervention to address clients' pressing needs, even where robust evidence of program effectiveness is lacking. In such circumstances, we encourage policymakers to employ the concept used in the CER policy community: "coverage with evidence development." Faced with inadequate evidence, policymakers can condition funding of a new care coordination initiative on the ongoing collection of data required to evaluate the program's effectiveness. We recommend that any new care coordination initiative or pilot should do the following: serve a well-defined priority target population; and occur within financing and organizational approaches that are potentially applicable to the broader target population of concern to the agency or organization funding the pilot program (to facilitate scaling up and replication by policymakers, if evidence justifies). We encourage program developers to use the conceptual framework, particularly the key dimensions shown in Figure 2, as a checklist as they decide how to structure a care coordination program. During program implementation, we recommend that practitioners clearly describe these dimensions to evaluators in order to determine how variation in these dimensions may affect outcomes. The evidence development phase (that is, data collection/program evaluation) should be long enough that benefits relevant to the decision makers will emerge and be detected, and it should include prospective planning for a credible evaluation.

Implications for future CER on care coordination for persons with disabilities. Our systematic review highlights how researchers can refine and improve evaluations of care coordination programs to better meet the information needs of decision makers (state governments, private payers, provider organizations). Whether the study is a prospective controlled trial or an observational study taking place in the context of "coverage with evidence development," researchers should try to ensure that the care coordination program has a clearly defined target population, and makes explicit the incentives or disincentives to coordinated care inherent in the program's organizational and financing setting.

To enhance the external validity of care coordination studies, researchers should focus on the effect of specific care coordination components. The conceptual framework presented here can help build the evidence base that will allow us to discern the dimensions of care coordination that are linked to better outcomes. To further develop the evidence and facilitate meaningful comparisons of effectiveness, outcome measures must be consistent from one evaluation to the next. Among the outcomes that are typically examined, health status appeared to be the one that is measured consistently (using the SF-12, and the SF-36). The same is not true for quality of life, patient satisfaction, and caregiver outcomes.

To be of greatest help to decision makers, evaluations must provide actionable information within a realistic time horizon and investigate care coordination interventions that can be readily scaled up for broader application in the community with the right incentives and support. Given the cost of care coordination implementation, the evaluation design will need to ensure internal validity of findings as well as assess their likely generalizability across a range of providers and delivery settings.

Traditional systematic literature reviews alone are not enough of a basis for developing a clear understanding of "what works" for an intervention as complex as care coordination.

A qualitative analysis would provide even greater insight into promising programs. For instance, interviews with program developers, participants, and staff would deepen our understanding of the elements of care coordination that are tied to improved outcomes. Finally, systematic literature reviews traditionally focus on published results from randomized controlled trials as the best source of information on impacts. Yet, quasi-experimental designs that evaluate programs in real-world, real-time settings, may be more relevant to policymakers. We encourage researchers to include these studies in literature review, provided that the quality of the evaluation design is assessed.

Limitations of this review. Despite the general inclusiveness of our systematic review approach, we also imposed restrictions that excluded evaluations of some interventions of potential interest to policymakers and program directors. Because we focused solely on care coordination as the intervention of interest, we did not review the literature on comprehensive care models, such as PACE, which include not only care coordination but also a complex combination of other core elements such as adult day care and capitated payments. This kind of larger system re-design, though proven effective, is much more difficult to implement and diffuse. Our review may be less helpful to those seeking information on system re-design (for example, accountable care organizations). Because our review focused on programs that served (exclusively or predominantly) persons with disability, we excluded studies of programs for older adults with chronic illness but not necessarily documented frailty or disability, like the Geriatric Resources for Assessment and Care of Elders (GRACE) program or the Guided Care model. We further limited our literature search to care coordination programs evaluated in the last decade within the United States health care system. Older evaluations of long-standing approaches to care coordination for adults with disabilities (for example, assertive community treatment for individuals with SPMI) were likely to have been excluded on this basis. Finally, we excluded evaluations of consumer-directed programs like Cash and Counseling that empower patients with disability, and their caregivers, to coordinate their own support services.

LITERATURE REVIEW METHODOLOGY

In collaboration with Mathematica research librarians, we conducted a literature search for primary research studies on the effectiveness of various care coordination programs for adults with disabilities. We searched 11 databases that index the published literature relevant to medical care, health services, psychology, and social services research; this search was completed October 20, 2010. We also searched for the “grey literature” using a Google engine we created; this search looked at websites for federal agencies, state agencies, health and disability professional associations, policymaker organizations, managed care organizations, and stakeholder/advocacy groups. A second Google engine search looked for specific program names based on feedback from technical experts in the area of care coordination for adults with disabilities. Searches were limited to articles published between 2000 and 2010.

To expand our understanding of what activities work best for each population, we sought information on select components of care coordination from the checklist shown in Figure 2: for example, (1) targeting strategies or tools to identify populations in need of services, (2) use of needs assessments, and (3) use of an individual or team to provide service/outreach. Study interventions that consisted of only one simple task of case management (for example, reminder phone calls to patients about medical appointments) were excluded because the concept of care coordination suggests more active management than would be possible with a single, simple contact. We also excluded models whose main intervention was to provide services in institutions (for example, nursing homes and hospitals) or short-term services associated with transitioning out of institutionalized settings. Our focus was on ongoing care coordination services that have the potential to optimize independent living for community-dwelling adults with disabilities.

In examining the evidence base for the effect of care coordination on outcomes for adults with disabilities living in the community, we included a range of disability categories: physical impairment, severe and persistent mental illness (SPMI), cognitive impairment, intellectual impairment/developmental disability, and sensory impairment. The search strategy covered population terms, outcome terms, and terms related to care coordination.⁷

Each title was scanned by two reviewers to ensure that we excluded those that did not concern a care coordination intervention or people with disabilities, as well as those focused on people residing in institutions (for example, nursing homes) or outside the U.S. All needed data were extracted independently by two trained reviewers.

Approach to grading evidence. In establishing a set of criteria for rating the quality of a study, we considered many existing systems for grading quality. Those used by the Cochrane Collaboration and AHRQ’s Evidence-Based Practice Centers (EPC) are among the best known, but these systems focus heavily on randomized controlled trials (RCTs) of clinical topics. Similarly, the GRADE (Grades of Recommendation Assessment, Development and Evaluation) system helps developers of clinical practice guidelines evaluate bodies of evidence and then determine the strength of their clinical recommendations. However, based on our knowledge of the existing literature on care coordination for adults with disabilities, we expected to encounter a much wider range of study designs than RCTs, as well as reports on a rich variety of complex human and social service interventions that differ qualitatively from drugs, medical devices, and even purely clinical treatment or diagnostic strategies. In addition, whereas the Cochrane and AHRQ systems rely heavily on implicit judgments by content and methodological experts, we preferred a system that used more explicit criteria in assessing the evidence.

We therefore decided to use the general approach developed for Mathematica’s other large-scale rigorous evidence-review projects, including the What Works Clearinghouse, Home Visiting Evidence of Effectiveness, and Pregnancy Prevention Research Evidence Review.⁸ Those studies faced similar challenges, namely providing policy-relevant assessments of a broad range of programs whose evaluations employed a variety of study designs. All addressed this challenge by developing formal evidentiary grading systems that could be applied to a variety of study designs.

⁷Additional details on the search strategy and terms can be found in the full report, which can be requested by emailing chce@mathematica-mpr.com.

⁸The findings from the last two projects have been widely used by policymakers and recently received recognition from the Department of Health and Human Services.

RESEARCH BRIEF

LITERATURE REVIEW METHODOLOGY

We assessed study quality only for studies that met all of our inclusion criteria.⁹ Our assessment focused specifically on the internal validity of a study's impact estimates. Although there are other features that determine a study's overall quality and usefulness (such as generalizability and the feasibility of replication), we did not include those dimensions in our assessments because of the lack of widely accepted or well-developed explicit criteria for evaluating them. Our rating system used a stepwise approach based on the following criteria:

1. Randomized study design
2. Absence of confounding factors (such as differential data collection procedures between study groups or a study group with only one sample member)¹⁰
3. An analysis that did not reassign subjects from one study group to another following randomization (also commonly known as "intention to treat")¹¹
4. Low attrition
5. Adjustment for statistically different baseline characteristics (or no significant baseline differences)

Studies received one of the following three ratings for internal validity based on the extent to which they met these criteria: high, moderate, or low (similar to the AHRQ EPC assessments of good, fair, or poor). Studies that met all five criteria were judged "high" internal validity studies. We assigned "moderate" ratings to studies that met the majority of these criteria and included statistical methods to compensate for deviations from these standards.¹² Studies that met none of the criteria or lacked statistical controls to compensate for deviations were assessed "low" internal validity studies. Table 4 summarizes the characteristics of studies for each rating category.

⁹These included the following: focus on care-coordination activities, inclusion of adults, focus on people with disabilities who are living within the community, study that tests an intervention and includes outcomes, and study published in 2000 or later that was implemented in the U.S.

¹⁰We follow the usage of "confounding" in the Pregnancy Prevention Research Evidence Review, the What Works Clearinghouse, and the Home Visiting Evidence of Effectiveness methods; this usage is different from the conventional usage of the term in the epidemiological, clinical, and biostatistical literature.

¹¹"Intention to treat" means that all participants are analyzed based on their original randomized status.

¹²Detailed description of the rating system is available in the full report, which can be requested by emailing chce@mathematica-mpr.com.

Table 4. Characteristics of Studies for Each Internal Validity Rating

High Internal Validity	Moderate Internal Validity	Low Internal Validity
Randomized controlled trial designs with:	Randomized controlled trial designs that:	Studies that do not meet the standards for a high or moderate rating, for example:
• No confounding factors	• Do not adjust for statistically significant baseline differences, but otherwise meet all criteria for high rating	• Quasi-experimental designs with no external comparison group (pre-post designs)
• Analysis with no reassignment of sample members	Quasi-experimental design or randomized controlled trial with high attrition or sample reassignment with:	• Quasi-experimental designs or randomized controlled trials that with high attrition that do not establish baseline equivalence
• Low sample attrition	• No confounding factors	• Studies with serious confounding factors
• Adjustments for statistically significant baseline differences	• Demonstrated baseline equivalence of samples	
	• Adjustments for baseline differences in the outcome measures	

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Health Care for Individuals with Intellectual and Developmental Disabilities: An Integrated DD Health Home Model

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Contents

1. Introduction	2
2. The Health Care Landscape	4
2.1. The Medical Home	4
2.2. Health Care Integration	6
2.3. Overview of the Patient Protection and Affordable Care Act	7
2.4. Health Care Funding	8
2.4.1. External Management of Utilization	9
2.4.2. Provider Payment Reform	11
2.4.3. Changing Patient Behavior	12
3. The DD Health Home Model	13
3.1. Description of the Model	13
3.2. Re-engineering of Care Practices	18
3.3. Reimbursement: Notes on Funding the Model	21
4. Outcomes and Evidence for Efficacy of the Model	22
4.1. Early Clinical Studies	23
4.2. Patient Satisfaction and Quality of Care	25
4.3. Utilization Studies	30
4.3.1. Early Utilization Studies	30
4.3.2. Recent Utilization Analyses	33
5. Conclusions and Lessons Learned	37
References	40

Abstract

In this chapter we present a community-based health care model for persons with intellectual and developmental disabilities (I/DD), the DD Health Home. We explore the

time, additional barriers to quality care for this group arise in systemic, organizational, and payment issues inherent in the American health care system.

It is now more than a decade since the surgeon general called attention to the “gap” between the care available in the mainstream American health care system and the medical care received by individuals with what was then known as mental retardation¹ (US Public Health Service, 2002). There is now a widespread recognition that fundamental flaws remain in the nation’s health care system, and that the Patient Protection and Affordable Care Act, signed into law by President Obama in March 2010, may not solve them all.² Nonetheless, health care for individuals with I/DD must be considered within the larger context and trends of the health care system in the United States.

Over the past quarter century, at least five trends have been clear with regard to health care in America: (1) health care costs have consistently increased, (2) health care has accounted for ever-larger portions of the nation’s GDP (gross domestic product), (3) health care reform has been controversial and contentious, (4) the proportion of states’ budgets devoted to health care entitlements has consistently grown, and (5) more than 45 million Americans have little or no access to health care benefits. It is against this backdrop that individuals with I/DD enter the health care marketplace and attempt to find appropriate medical services—it can be a daunting quest.

However, prior to the Affordable Care Act, a spirit of reform was already beginning to grow in the nation’s health care sector leading to an increased recognition of what has been called the “triple aim” of health care (Berwick, Nolan, & Whittington, 2008). According to Berwick and his colleagues, the goals for American health care that define this *triple aim* are “improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations.” (p. 760)

In this chapter, we present an overview of the health care landscape for persons with I/DD, a brief review of aspects of the Affordable Care Act that relate to persons with I/DD, as well as a model of community-

¹ This paper will use the term “intellectual and developmental disabilities” or I/DD to refer to the population in question.

² At the time of this writing, the US Supreme Court had heard oral arguments on aspects of the Patient Protection and Affordable Care Act and ruled on 28 June 2012, by a 5-4 margin, that the law was constitutional. The term “Affordable Care Act” will be used to refer to this law throughout.

Lack of access has been especially problematic for persons with I/DD resulting in the service gap identified in the Surgeon General's report.

As concerns about primary care grew in America (Bodenheimer, Grumbach, & Berenson, 2009; Bodenheimer & Pham, 2010; Phillips & Bazemore, 2010), the interests of policymakers and health care providers became aligned and they aimed to strengthen the role of primary care providers. Strengthening primary care was seen as a way to reduce health care costs and improve quality (Berenson et al., 2008). As these powerful ideas spread, in addition to the AAP, the AAFP and the American College of Physicians (ACP) developed their own models for improving patient care under the rubrics of the "patient-centered medical home" (AAFP) or the "advanced medical home" (ACP, 2006).

In March 2007, the AAP joined with the AAFP, the ACP, and the American Osteopathic Association to publish a joint set of principles on the patient-centered medical home (AAFP, 2007). This consensus statement describes the principles of the medical home. These principles include access to a personal physician in a physician-directed medical practice, a whole person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment.

Thus, the medical home is not a place; rather, it is an approach to primary health care delivery that provides individuals with timely, well-organized care and enhanced access while reducing service disparities due, for example, to disability. The medical home concept emphasizes care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. It also promotes equity in health care by integrating services and supports that assure individuals receive the right kind of care, when they need it, in an appropriate setting (Beal, Doty, Hernandez, Shea, & Davis, 2007).

A key element of the medical home is the capacity to coordinate care. For persons with developmental disabilities, this coordination of care is vitally important because of the frequency of comorbid conditions. Several entities need to be coordinated including primary care practitioners, medical specialists, tertiary health care providers such as hospitals and rehabilitation centers, allied health professionals, and ancillary services including durable medical equipment (DME) vendors and pharmacies (AAP, 2005; Criscione, Walsh, & Kastner, 1995; Kastner, Walsh, & Drainoni, 1999). In addition, for individuals with I/DD, health care interventions need to be integrated with the social supports available to the individual including family, school, work, and paid caretakers.

America. As noted at the outset, that system is in flux. New ideas are being sought and developed to reform American health care; many of these new ideas are embodied in the Affordable Care Act. A brief overview of the law and an overview of health care funding approaches are provided as a prelude to presentation of the DD Health Home.

2.3. Overview of the Patient Protection and Affordable Care Act

Although quite complex, the Affordable Care Act highlights a number of important trends that will affect all health care reform efforts in America going forward. Signed into law on 23 March 2010 by President Obama, the law was originally challenged on several fronts by states, organizations, and individuals, although in upholding the law, the Supreme Court may have blunted many of these challenges. Regardless, these concerns are of less interest here; rather, more important in this context is the impact the novel ideas contained in the Act may have on American health care in general and persons with I/DD in particular. The Affordable Care Act includes many provisions, some of which became effective when the law was signed, and others that were deferred and either have already taken effect or are scheduled to take effect on dates stretching out to 2020.

In its entirety, the Affordable Care Act provides a blueprint for how health reform is likely to progress. For example, the Act includes important changes in the way health care is delivered and how reimbursement systems pay for it. It emphasizes health care outcomes as opposed to medical procedures and retrospective payment. The Act created an independent, nonprofit, patient-centered outcome research institute with the goal of shifting the focus from procedures to patient outcomes. Additionally, it created a council within the US Department of Health and Human Services focused on prevention and health promotion. Provisions such as these signal a shift in health care emphasis away from traditional approaches of simply treating diseases, toward prevention, health promotion, and improving health outcomes. In fact, beginning on 1 January 2015, the Affordable Care Act requires that payment for physicians' services be modified such that payment is made on the basis of quality of care, and not on the volume of patients and procedures.

The Affordable Care Act has brought to light the fact that much spending on health care in America may do little to actually improve the health of the nation's citizens. For example, health care dollars are often

In order to survive, the DD Health Home described below requires a business model that simultaneously supports health promotion and reduces costs. But to understand the business model underlying the DD Health Home, it is necessary to understand current approaches to cost containment. Three broad approaches to cost containment will be briefly described: (1) approaches that relate to external management such as Health Maintenance Organizations (HMOs), (2) provider payment reforms including Accountable Care Organizations (ACOs), and (3) incentives to change consumer behavior.

2.4.1. External Management of Utilization

In 1973, Congress passed the Health Maintenance Organization Act. This Act encouraged the growth of HMOs, which were the first form of managed care. At first, it was thought that HMOs could control costs through "capitated" payment systems. In a capitated system, instead of being paid for each service, practitioners are paid a set amount each month for each of their patients for providing all of the care needed. At present, approximately 90% of insured Americans are enrolled in plans with some form of managed care, although the use of capitated payment systems in managed care is not as widespread as might be expected.

Furthermore, although HMOs are the predominant form of managed care, the term has now broadened to describe a variety of organizations. Managed care companies now include insurance companies, administrative services organizations, disease management organizations, and other health management companies. To manage costs, these organizations use a wide range of techniques including preauthorizations for care, concurrent review of proposed care, retrospective review of practice patterns, the use of formularies (lists of approved medications) to control pharmacy costs, and in-hospital discharge planning programs. Patients now commonly encounter medical procedures that cannot go forward, or prescriptions that cannot be filled, until the payer has approved them.

Over time, many health management organizations have blended care management concepts with utilization management activities. Unfortunately, the intent of traditional utilization management was solely to control costs, typically by restricting access to care in one way or another. Care management on the other hand, arose in the context of coordinating care to improve quality. Regardless, the term "managed care" has now come to signify a general philosophy of cost containment rather than any specific management approach.

government to implement it by 2014. Under the Affordable Care Act, states will be permitted to enact single-payer systems beginning in 2017. Many Americans continue to see single-payer systems as a viable solution to coverage for all citizens. Vermont is likely the first of several states that will seek to implement single-payer systems under the Act.

2.4.2. Provider Payment Reform

Efforts to reform payment to providers have been directed at aligning the incentives of the provider with those of payers, which are government entities for Medicare and Medicaid. These efforts are characterized by attempts to eliminate the incentive of providers to increase service utilization and require that the practitioner assumes some degree of financial risk for managing the future health care costs of patients. For example, in fee-for-service models, a health care provider bills for each service delivered to a patient. In the future, however, providers will be asked to take more responsibility for the overall health of patients. Having providers shift their focus to the overall health of patients will likely be accomplished by capitating payments in *prospective* payment systems. That is, a health provider will be paid a specified amount for each patient which, when aggregated, will constitute a budget for the provider. If service utilization is below what is budgeted, the provider earns a profit; if utilization exceeds what was anticipated, the provider assumes a financial loss.

In small populations with substantial variability among members, such as in persons with I/DD, this risk may be too great to bear. Being able to bear risk through capitation payments depends on the ability to predict future health care use. Predicting health care use, however, may be particularly difficult for persons with disabilities, a fact that would provide a disincentive for providers to serve persons with I/DD. In the end, capitated systems favor larger providers because risk can be spread over a larger group.

Furthermore, the actuarial approaches used to predict future health care use and establish costs, such as relying on procedure codes (e.g. CPT or ICD-9 codes) or on past history, are often not especially accurate. As a result, risk capitation is associated with larger organizations and poses greater financial risk when applied to small providers (Cox, 2010). Therefore, going forward, actuarial uncertainty will favor larger organizations, whether they are provider or insurance based. Such uncertainty represents yet another argument for the inclusion of individuals with I/DD in larger health care systems.

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sharing did not significantly affect the quality of care received by the study participants, although it reduced the use of nearly all health care services. However, the reductions in health care use did not distinguish between the consumption of effective or less-effective care—both types of care were reduced about the same. Quality of care was problematic across all conditions and also was not differentially affected by cost-sharing conditions. Furthermore, despite the fact that health outcomes were not significantly different than in other groups, patients assigned to the HMO condition were less satisfied with their care. The authors concluded, in general, that cost sharing reduced costs but did not have adverse effects on the general health of participants. Reductions in costs through cost-sharing plans, without associated loss of quality, have led to calls for an expanded role for cost-sharing payment models.

However, based on the general lack of consumer enthusiasm and the lack of additional empirical support, advocates concluded that cost sharing, even if it were possible under current Medicaid rules, should not be applied to Medicaid beneficiaries, particularly those in Aged, Blind, and Disabled programs. For now, substantial cost sharing in public programs does not seem to be on the horizon although it could find its way into the Medicaid and Medicare programs after the implementation of external management and payment reform measures. Many states already impose co-pays on some Medicaid beneficiaries for certain services (such as emergency room use or some pharmaceuticals). Shifting a greater share of costs and responsibility to Medicaid beneficiaries would increase the value of the medical home as it will create financial incentives for consumers to seek information that can not only improve health but also reduce personal expenditures as well.



3. THE DD HEALTH HOME MODEL

3.1. Description of the Model

These health care and reimbursement reform ideas may seem disparate and confusing at first. However, it is possible to organize these ideas into cohesive health care models that can benefit persons with I/DD. The DD Health Home is such a model. The DD Health Home provides comprehensive primary health care services in normalized, community-based office settings that go beyond typical primary care to incorporate care coordination and elements of specialty care. Aspects of the model have been previously described in the literature under different names (Kastner & Walsh, 2006;

disabilities. Although the structure of the DD Health Home offices is adapted in many ways, offices are little different than a typical doctor's office. Nonetheless, the medical encounter processes and the practitioner services *are* remarkably different. In the DD Health Home, the typical primary care office visit has been wholly re-engineered to meet the needs of individuals with I/DD (Berenson et al., 2008; Casalino, 2010; Friedberg, Hussey, & Schneider, 2010; Kastner, 2004; Philips, O'Chesky, & Kastner, 1995).

Although many of the typical services of a primary health care setting are provided (see top part of Table 1), they are specialized for the I/DD population. A defining element of the DD Health Home is health care coordination—a function carried out by the nurse practitioner who also delivers primary care. Care-coordination functions include regular telephone contact with patients, ongoing assessment of treatment compliance, making and coordinating routine appointments with health care providers, follow-up clearance for hospitalizations and emergency room visits, updating electronic medical records, and fulfilling documentation requests.

The DD Health Home model goes beyond typical primary care services by *integrating* mental health services and specialty medical care including

Table 1 DD Health Home Service Areas

Area	Service
Primary care	Annual physical examinations
	Acute care office visits (diagnostic assessment and treatment)
	Ongoing care for chronic conditions
	Care coordination
	Medication management
	Preadmission screenings
	Postemergency room and posthospitalization follow-up visits
	Health screenings (e.g. breast cancer)
	Disease prevention (e.g. immunizations)
	Health promotion activities (e.g. nutritional counseling)
	Blood draws
	Tuberculosis testing
	Immunizations
	Camp physicals
Specialty care	Service provider documentation
	Mental health diagnostic assessment and treatment
	Psychiatric medication management
	Primary neurology (seizure management)
	Gynecological examinations

diagnoses, receive coordinated care, monitoring for medication interactions and side effects as well as regular review of the effectiveness of all relevant treatments as part of their routine care. Thus, I/DD patients who present with multiple conditions often receive appropriate care without the need to coordinate two or more completely independent practitioners.

The core of the DD Health Home clinical practice model is a team approach that relies on an interdisciplinary relationship between physicians and nurse practitioners. Firmly entrenched in the model is the principle that nurse practitioners can serve multiple roles as effective team leaders, clinicians, and care coordinators—a view which finds currency in recommendations for transforming the larger health care system (Bauer, 2010; Bodenheimer & Pham, 2010; Naylor & Kurtzman, 2010). In the model, nurse practitioners take the lead and provide primary care as well as mental health and basic neurological care (i.e. seizure management); however, they also have access to physician specialists who provide support and enhance their practice patterns.

Because the DD Health Home is an expanded primary care model, long-term relationships are developed between patients and practitioners in the medical office sites. In this way, continuity is built into the model based on the limited size of the practices and the caseloads of individual practitioners. Experience and patient surveys have shown that patients become close to the physicians and nurse practitioners and value the continuity and personalized care available in the model. This broader sweep of care and its coordinated management are designed to achieve the triple aim of better care, better health, and lower costs.

A few examples will illustrate. A profoundly disabled young man who had lived at home with his mother and grandmother and according to them had “never been to a doctor” presented in a DD Health Home office. As part of the enrollment process for a day program, he needed a simple Mantoux test for tuberculosis (TB). The lack of this test had prevented his day program enrollment for more than a year. The problem was that he was fearful of the intradermal injection required, and became aggressive toward health care workers who approached him. To counter this behavior, the young man was scheduled to come to the office repeatedly over the course of a month. During these visits, he had coffee with staff members and was allowed to freely explore all the rooms. In addition, simple procedures such as taking his temperature and taking his blood pressure were carried out to desensitize him to medical procedures. On his fourth visit, the TB test was successfully administered and on his sixth visit, a successful blood draw was

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1990s (Criscione, Kastner, Walsh, & Nathanson, 1993; Criscione et al., 1995; Kastner & Walsh, 1999; Philips et al., 1995; Ziring et al., 1988). This work delineated the roles and responsibilities of the team members and ascribed to nurse practitioners an independent practice role as well as a care-coordination role. Nurse practitioners were seen as working independently although, at the same time, collaboratively, with physicians and other personnel serving the patient (Philips et al., 1995).

As noted, to achieve improvements in overall health care, nurse practitioners in the DD Health Home are cross-trained in basic mental health and neurological care which serves to integrate these specialties with primary care treatments. This cross-training is vitally important to both the quality of care and the cost savings because mental health issues and seizures are common comorbidities in this population. When these components are not integrated, patients are typically sent to independent specialty practitioners with, as described above, the potential for different practitioners to work at cross-purposes. For reasons such as these, and because specialists are often difficult to reach, the model also simplifies communication through its 24/7 on-call access to nurse practitioners.

In the DD Health Home, the primary care provider occupies a central place—primary care is considered to be the first point of contact in all health care encounters. In this way, the use of emergency departments and hospital admissions are reduced or avoided. In the model, *primary care* has been redefined and re-engineered to incorporate more than what typically passes for primary care in other systems. The integration of primary care and selected specialty services maintains the client as the focal point of care (e.g. Berenson et al., 2008).

Additionally, such integration is directly related to the nature of this population because, as a group, persons with I/DD have higher rates than the general population of comorbid conditions and of sensory and other physical disabilities. Associated conditions such as sensory deficits, speech problems, ambulation and gait disabilities, metabolic disorders, and higher rates of mental health and psychiatric disorders complicate the care of this group. Patients with I/DD also exhibit predictable rates of complex behavioral problems arising separately or in conjunction with mental health problems, adaptive skill deficits, or environmental factors. Because of these characteristics of I/DD patients, nurse practitioners take the lead and provide primary care as well as mental health and basic neurological care (i.e. seizure management). At the same time, however, they have access to internal medicine physicians who support and enhance their individual practice patterns.

linking with all available case managers working with a patient and, if necessary, they can provide a coordinating function among them in order to maximize positive health outcomes.

Nurse practitioners in the DD Health Home are able to tailor care to individual patients and efficiently arrange resources, including preventive services, hospital admissions/discharges, home care, inpatient and outpatient surgery, medical equipment, and pharmacy services. Through regular telephone contact with patients, nurse practitioners are able to identify atypical needs, avoid unnecessary utilization, ensure compliance with medications and other recommendations, encourage improved diet and self-care, and coordinate family and community resources. In short, the positive effects and outcomes of primary care are enhanced because the treatment interventions for the patient in the DD Health Home are directly structured around the person's needs.

3.3. Reimbursement: Notes on Funding the Model

Transforming care practices requires a change in how the DD Health Home is reimbursed for services. In this regard, it is important to understand whether the I/DD population is considered to be part of the larger health care population (Kastner & Walsh, 2006). Patients with I/DD can be included in a larger system (which is referred to as *carved in*) or they can be part of a payment system, with potentially higher rates, that is established separately from the system in which the general population is funded (referred to as *carved out*).

There are benefits and drawback in both approaches. For example, when the I/DD population is carved out of general payment structures, it may be easier to provide the highly specialized services needed by this group. However, because the services are highly specialized and the providers bear no risk, such services may become quite costly and yet remain protected from the forces that serve to lower costs in larger systems.

From the foregoing discussion, it is clear that the major goal of the DD Health Home is to have practitioners focus on improving the health of patients rather than on simply generating income under a fee-for-service arrangement. Because many patients with I/DD use more health care services than persons in the general population, the DD Health Home is exposed to "adverse selection"—a term given to the phenomenon that occurs when a health care provider attracts patients who are sicker or require more services than others.

into three broad categories: (1) early clinical studies that supported the re-engineering of the medical encounter as well as the development of clinical guidelines; (2) patient satisfaction and quality of care studies, and (3) utilization studies showing the effects of the model on outcomes such as costs and hospital and emergency room use. The results of utilization studies are becoming especially important during a period in which American health care policymakers are considering how to reconfigure the nation's health care system and practitioners are addressing improvements in patient care. Each category of studies will be described, in turn, and evaluated against the triple aim outlined by Berwick and his colleagues.

4.1. Early Clinical Studies

From a scientific perspective, one of the benefits of the specialized clinical practice in the DD Health Home is that it provides a concentration of patients with I/DD for clinical and applied studies. Over the years, the model has produced many published reports that, taken together, speak to the goals of improving the clinical care of patients with I/DD as well as contributing to the knowledge needed for evidence-based practices. There have been efforts to create practice guidelines in diverse areas of care for disabled persons such as primary care (Kastner, 2004; Sullivan et al., 2011), screening and diagnosis in autism (Filipek et al., 2000), nutritional services (American Dietetic Association, 2004), and cytogenetic evaluation (Shaffer, 2005). But until a quarter century ago, there were few resources upon which practitioners could rely. It was this paucity of clinical research findings that, in part, prompted the applied and clinical studies noted below that were carried out in the DD Health Home.

Over the past 25 years, a number of clinical topics have been identified and studied. These include the following:

- Predental prophylaxis screening for heart disease in persons with Down syndrome (Barrett, Friedman, & Kastner, 1988);
- Screening for thyroid disease in persons with Down syndrome (Friedman, Kastner, Pond, & O'Brien, 1989);
- Measuring effectiveness of valproic acid in the treatment of children with developmental disabilities and mood disorders (Kastner & Friedman, 1992; Kastner, Friedman, Plummer, Ruiz, & Henning, 1990; Kastner, Walsh, & Finesmith, 1993);
- Improving immunization rates against pertussis in children born prematurely (Kastner, Ruiz, & Nathanson, 1991);

practice guidelines address the specific clinical care issues of a host of medical syndromes that often affect patients with I/DD such as gastrointestinal disorders, tardive dyskinesia, mood disorders, feeding disorders, and patient evaluation and assessment issues.

What is more important is that the operation of this model over the past 25 years has given rise to a knowledge base, most of it published, that provides a foundation of clinical knowledge in the provision of quality health care for persons with I/DD. That is, this knowledge helps to inform routine primary care delivery, but has also had a salutary effect on the redesign of the practice setting (Berenson et al., 2008; Bodenheimer & Pham, 2010). Thus, as clinical findings were studied and conclusions were drawn, relevant changes in practice were inculcated into the model. In this way, this body of work clearly addresses the need of health care systems to "improve the health of populations" as articulated by Berwick and his colleagues (2008) on the triple aim of health care systems.

4.2. Patient Satisfaction and Quality of Care

Patient satisfaction and quality of care have long been important components of primary care practices (Daley, Gertman, & Delbanco, 1988; Walsh & Kastner, 1999) and have remained valued health care outcomes (Browne, Roseman, Shaller & Edgman-Levitan, 2010; Safran, 2003). Over the past two decades, the quality of health care has received extensive attention in the research literature. For example, a search of the Medline database between 1996 and the end of April 2012 using the search term "quality of health care" returned nearly 33,000 items. To assess patient satisfaction and care quality within the DD Health Home, a number of patient surveys were conducted using a carefully designed survey form that addressed critical domains of care.

At the time these efforts were initiated, there were few guideposts and no assessment instruments for the quality of primary care or patient satisfaction in this population. Therefore, a survey form was developed specifically for use in the multiple offices that shared the model. At that time, interest in measuring the overall quality of life in persons with I/DD was also escalating (Schalock, 1990; Schalock, Keith, Hoffman, & Karan, 1989). Unfortunately, this interest did not generally extend to health care quality measures. For example, Hughes, Hwang, Kim, Eisenman, and Killian (1995) in their extensive review of research published between 1970 and 1993 identified 1243 specific quality measures which they classified into 15 dimensions. The

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parents, three (2.4%) were siblings, 100 (80%) were staff or paid caregivers, and two (1.6%) were "other" (a therapist and a state caseworker). Of the 89 staff or paid caregivers who identified their position, 69 (77.5%) were at the direct care level and the remaining 20 (22.5%) were supervisory-level staff members.

Results from the survey suggested that the clinical services offered within the DD Health Home are highly valued by respondents. With regard to access to services, 99% of respondents reported that they were able to schedule appointments without delay and 97% agreed that phone calls to the offices were handled efficiently and effectively. As noted earlier, the average waiting room time was 6.9 min [standard deviation (SD) = 7.4]. Over 90% of respondents rated as either "very good" or "excellent" the ease of driving to the offices (95%), parking at the offices (91%), and aspects of the physical access to the waiting/exam rooms (97%).

On the quality of care received, respondents "agreed" or "strongly agreed" over 90% of the time with statements about (1) the quality of care on the day of the survey visit (95%); (2) questions being fully answered and necessary information being provided (99%); and (3) that they experienced consistency and continuity in who provided their care (98%). Furthermore, over 98% of respondents agreed or strongly agreed that office visits were long enough, that the primary care practitioner listened to concerns, and that medical staff members were respectful to them. Positive ratings were also found for clerical staff with over 99% of respondents agreeing or strongly agreeing with statements that the clerical staff members were knowledgeable, courteous, and efficient. Twenty-four percent of the respondents rated the comfort of the waiting rooms good while 74% rated them as excellent and, once again, 99% of respondents agreed or strongly agreed that sufficient privacy was afforded during the health care visit.

In regard to the health status of the patients surveyed, 90% of respondents agreed or strongly agreed that the health of the person had improved during the year and 93% reported that the DD Health Home helped to keep them healthy. Supporting this finding of better self-reported health status, were reports that 88% of the patients surveyed continued to participate in day activities outside their home; 78% reported independence in walking, with the remainder reporting either the partial ambulation abilities (10%) or the inability to walk independently (13%).

On this survey, optional written comments were provided on 88 survey forms (49%) with comments being overwhelmingly positive. For example, a residential program director added this comment to a survey form:

Table 2 Written comment thematic coding results

Theme codes	Theme code designations	No. of "mentions"	Total "themes" (%)
1	Staff characteristics	35	28%
2	Service structure	6	5%
3	Service processes	11	9%
4	System issues	2	2%
5	Service quality	19	15%
6	Other positive	46	32%
7	Negative	12	10%
	Total	131	101%*

* Exceeds 100% due to rounding.

expected to produce negative comments because the instructions asked respondents to note what they *like* and what they *don't like* about their health care services. Five comments included both "likes" and "dislikes" and all of these were included under theme #7. The negative comments identified under this theme typically referred to areas other than health care such as waiting room concerns (e.g. wanting a television in the waiting room, or requesting a better magazine selection) or concerns about parking.

As shown in Table 2, the bulk of the comments (75%) were categorized into only three thematic areas: (1) positive comments about staff members (35 comments), (2) positive comments about the quality of services (19 comments), and (3) other general or nonspecific positive comments (46 comments).

Taken together, the survey findings and comments reveal that the array of primary care services and the manner in which they are delivered are highly valued. However, these findings are not necessarily surprising in terms of reports in the literature showing that health care consumers prefer easy access to services, longer clinical visits, and more communication from practitioners (Browne et al., 2010; Liptak et al., 2006; Lown, Rosen, & Marttila, 2011), elements that have been specifically included in the DD Health Home.

Of importance here is that these findings on satisfaction clearly address another of the elements of Berwick's triple aim for health care, namely that the "experience of health care" be improved (Berwick et al., 2008). These results mirror those from prior years and show that patients and/or their proxies are satisfied with their care experiences and believe that they enjoy better health because of them.

It was hypothesized that the care-coordination component of the DD Health Home model would result in more efficient management of patients overall, including while they were in the hospital, and in this way reduce hospital utilization to produce a cost savings. It was this hypothesis that the research program initially set out to test. Three studies were published in the 1990s that are particularly relevant to this question—Criscione et al. (1993, 1995) and Walsh, Kastner, and Criscione (1997).

In the first study (Criscione et al., 1993), patients with I/DD who had been admitted to a hospital during a single year were identified and divided into two groups—one group was from the DD Health Home and had nurse practitioners serving as care coordinators (the care-coordination group) and the second group consisted of admissions made by community physicians without care coordinators (the usual-care group). Individuals in the care-coordination group had 22.7% shorter hospital stays, just under two fewer days on average, than did the usual-care group. When length of hospital stay was adjusted for case mix using the DRG coding system, the difference increased to more than 3 days ($p < 0.05$) (Criscione et al., 1993).

Because patients in this population often have multiple hospital admissions in a given year, this study also examined the number of inpatient admissions during the year and found that the average number of admissions was significantly higher in the usual-care group (mean = 1.6, SD = 0.99) than in the care-coordination group (mean = 1.2, SD = 0.45) ($p < 0.02$). In the care-coordination group, only 13.9% of the patients were admitted more than once during the year compared to 34% of the usual-care group. These findings supported the hypothesis that care coordination had an effect on hospital utilization and was a valuable addition to the array of primary care services in the model. The next study in the series (Criscione et al., 1995) sought to replicate these findings and extend them.

This study retrospectively identified all hospital admissions of individuals with developmental disabilities over a 3-year period and again divided them into a usual-care group and a care-coordination group. Hospital utilization (length of stay) and costs (hospital charges) were compared. Once again, comparison of the length of hospital stays showed the effects of care coordination. The average length of stay in the group of patients who received care coordination through the DD Health Home was 36.6% shorter than the length of stay of individuals without care coordination (the usual-care group). When the length of stay measure was adjusted for the *case mix* of the groups (i.e. adjusted for severity, complexity, and comorbidity), the difference was even larger—after adjustment, the care-coordination group

replicate the two-group comparison approach of the two studies described above, results showed that, over the study years, per-case hospital costs for the group of patients from the hospital including the DD Health Home patients (the coordinated dataset) increased far less (43.3%) than per-case costs in either the general developmental disabilities population (97.1%) or the nondisabled population in general (124.7%). These findings, once again, point to the beneficial impact of care coordination on hospital costs.

At a time when health care services in many states for persons with I/DD are not integrated, with providers dispersed in various "silos" that further inhibit coordination, the lesson in these utilization studies continues to be relevant—that is, that health care coordination represents an efficient component of primary care. Furthermore, health care models, such as the DD Health Home, that have strong care-coordination components, are likely able to reduce the costs of care for patients with I/DD by providing an integration function across different elements of the health care and wider service systems.

Not only did these studies provide initial validation for the DD Health Home model but they replicated other findings that were being reported in the literature for similar populations such as children with chronic conditions (Liptak, Burns, Davidson, & McAnarney, 1998). Thus, the findings were seen as important and very relevant to questions about the costs of provision of primary care and care coordination to individuals with I/DD (Kastner & Walsh, 1999).

4.3.2. Recent Utilization Analyses

In the late 1990s and early 2000s, the DD Health Home office location moved from the original hospital base to a number of integrated community-based office settings. At the same time, the State of New Jersey began to move the health care for Medicaid-eligible individuals, including those with I/DD, from fee-for-service Medicaid to Medicaid managed care. To assure continued funding for the model, contracts with Medicaid HMOs were developed and the challenges of serving I/DD patients through Medicaid managed care were addressed (Kastner, Walsh, & Criscione, 1997a, 1997b; Ronder, Kastner, Parker, & Walsh, 1999; Walsh & Kastner, 1999).

The movement of patients into Medicaid managed care provided additional opportunities to evaluate costs and utilization in the DD Health Home model. During the past decade, the model has been evaluated in relation to payment systems operating in managed care networks. A common measure of economic performance in managed care is the health

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Table 3 Means and SDs for outcome measures (3 years)

Outcome measure*	DD Health Home group		Usual-care group		p Value
	Mean	SD	Mean	SD	
Emergency room visits	2.05	2.37	6.59	16.11	$p < 0.001$
Emergency room visits (outliers removed)	2.05	2.37	4.24	5.49	$p < 0.001$
Hospital admissions	0.43	0.80	1.29	4.28	$p < 0.007$
Hospital admissions (outlier removed)	0.43	0.80	0.91	2.11	$p < 0.008$
Average length of hospital stay	1.60	3.53	1.58	3.49	Not significant

* All outcome measures are *per person per year*.

attesting to the importance of the health home approach. Group differences in the average length of hospital stays were not significant.

Overall levels of emergency room use in this study are likely to be high in relation to national norms. New Jersey is unique in that long-term care staff members are required by a state law, Danielle's Law (2003), to call 9-1-1 when they believe that a person with I/DD is experiencing a life-threatening event or illness. Because the law includes individual civil penalties, it has emerged as a major driver of emergency room utilization for this population in the state. This fact, along with the large SDs in the usual-care group, once again suggested that there were disproportionate values, or outliers, in the dataset. To identify outliers an arbitrary, but generous, figure of more than 40 emergency room visits per year for an individual patient was adopted as the criterion for a case to be considered as an outlier in the emergency room data. Remarkably, a search of the data identified five individuals who exceeded this criterion—all of whom were found in the usual-care group. Together, these five subjects alone accounted for 457 visits to the emergency room over the 3-year study period! Individually, these five outliers accounted for 119, 62, 42, 118, and 116 emergency room visits, respectively.

As in one of the utilization studies reported earlier, the data were reanalyzed with the outliers removed. Without the five outliers, the group difference for emergency room visits was somewhat attenuated but remained statistically significant (see Table 3). Similarly, a single outlier with 50 hospital admissions in a single year was found in the usual-care group when the hospital admission criterion was set at more than 20 in a given

charges in 2009 for a single inpatient encounter was \$17,089 resulting in a savings of more than \$1.86 million. In short, with regard to the part of the triple aim having to do with reducing the population costs of health care, the DD Health Home clearly achieves such savings.

5. CONCLUSIONS AND LESSONS LEARNED

Many forces, such as state Medicaid budgets, the Affordable Care Act, new payment methods and systems, and the emergence of various approaches to managing care, are changing how health care is delivered to Americans, including persons with I/DD. These changes are likely to reshape the traditional safety-net providers who served this population and will prompt movement of persons with I/DD into normative health care systems. Although inclusion in larger health care systems may be beneficial for some individuals with I/DD who do not have many health concerns, for those with more health care needs, movement into mainstream health care structures could be problematic.

Still, health care reforms, as well as innovations in the practice and delivery of health care, hold great promise for all patients, including those with I/DD. However, this promise will be empty if problems of health care access continue to plague the population, or if access is achieved but there are no appropriate services, or if limits are placed on those services that are available. The realization of the triple aim of health care—better health care experiences, improved health outcomes, and cost efficiencies—must apply to this group just as it does to patients without disabilities. If these aims are not achieved, persons with I/DD may continue to be underserved despite improvements in the overall health care system.

One way to assure inclusion in the complex and changing American health care landscape for individuals with I/DD is to create medical homes that have the capability to provide specialty care to the I/DD population while also securing a place in the larger health care system. The DD Health Home described herein is such a medical home. To survive in the general health care marketplace, the DD Health Home must achieve the contemporary health care goals in the triple aim and, at the same time, create fundamentally sound payment structures. Prospective reimbursement systems for specialized I/DD medical homes must take into account the barriers to health care in this group, the challenges of providing medical care, and the need for health care coordination.

Fifth, evaluation of the DD Health Home has benefited from the analysis of clinical and systems outcome data. These data, in turn, have been linked to changes in the delivery of health care through the model. One example is that the results of clinical studies were used to alter medical practice. Another example was that, as the impact of care coordination became clearly validated, it was an easy step to move to examining other outcomes—such as patient satisfaction and quality of care.

Finally, experience in the DD Health Home clearly revealed the extent of inefficiencies that exist in the health care of this group. Studies of the model uncovered excessive numbers of hospitalizations and emergency room visits—even for patients enrolled in managed care programs. Future work needs to continue identifying and addressing such inefficiencies in the system. For example, future studies might profitably examine pharmacy costs or DME consumption. Beyond that, it is possible that health home practice models may reduce reliance on long-term care. Most professionals in the field have encountered cases in which long-term care placement has been sought primarily because it provided access to clinical services. Unfortunately, all of these inefficiencies simply waste valuable resources and have a negative impact on the overall quality of care.

In the end, the DD Health Home is an important primary care model that can facilitate the development and delivery of high-quality health care to individuals with I/DD. Work to date shows that the model is efficacious and is able to address the triple aim of health care—better care, better health, and lower costs. Although the DD Health Home presents an approach to developing high-quality health care for individuals with I/DD, there is much to do.

Nationwide, many, if not most, patients in this group are still struggling for access in Medicaid fee-for-service systems, or increasingly are being enrolled in managed care structures which may further inhibit choice without providing any offsetting benefits. In this paper, we have described an alternative model of health care—the DD Health Home—that is normative, integrated, and appropriate to the needs of persons with I/DD.

Fortunately, the DD Health Home model will continue to be a subject of study as the model received a 3-year federal demonstration project award from the Center for Medicare and Medicaid Innovation of the Centers for Medicare and Medicaid Services. This will allow for the opening of additional DD Health Home offices in New Jersey, New York, and in Little Rock, Arkansas. As part of the demonstration program, outcomes studies such as those reported herein will continue.

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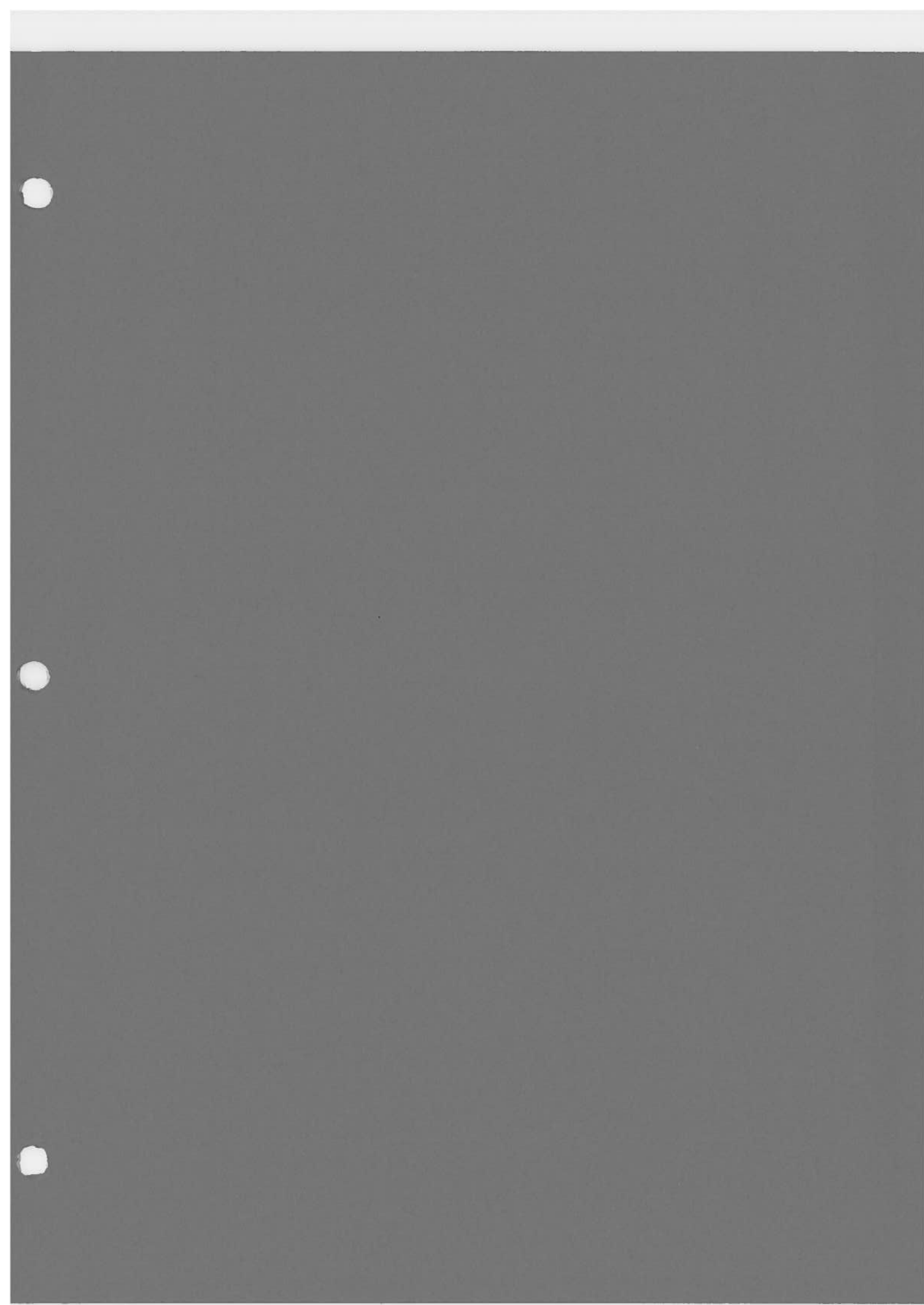
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*CareConnect Focus Group
Nashua, New Hampshire
November 6, 2013*

Participants – Billy Abbott and Nancy Ferrell, Nashua Center; Darlene Foley, PLUS Company; Anita , parent; Sheri Lupien, IPPI; Bill Stumpf, Gateways; and Barbara , parent
Facilitator – Susan Covert

In order to better understand how individuals with disabilities access and utilize health care services, the CareConnect Disabilities Home Health Project hosted an evening focus group on November 6, 2013 at Dartmouth Clinic in Nashua. Those invited included: two men enrolled in CareConnect, three parents, and representatives from five agencies (Gateways Community Services, Plus Company, Office of Public Guardian, Institute of Professional Practice, and the Nashua Center) that serve individuals participating in the CareConnect Project.

The day of the focus group, one parent came down with the flu and had to cancel. Unfortunately, neither of the men enrolled in CareConnect were able to attend. One man could not get time off from work and the other called his driver from the emergency room to say he was being admitted to the hospital. The Office of Public Guardian was unable to send a representative to the focus group.

Seven individuals participated in the two-hour discussion. The group included two parents who have adult daughters with disabilities and five service professionals, including two registered nurses, from four agencies that serve individuals with disabilities in the Greater Nashua area.

The evening began with Jessica Gagnon, Health Services Coordinator, and Carolyn McLaughlin, Community Navigator, providing an overview of CareConnect and talking about their respective roles in the project. Jessica and Carolyn did not stay for the focus group discussion.

Individuals with Disabilities and the Health Care System

The focus group was organized around a set of questions drawn up by the CareConnect planning team. Parents and providers were asked to share the experiences that their family member or the people they serve had in accessing and utilizing health care services. The focus group's

Company asks that staff speak with the agency's nurse before calling the doctor's office. Staff provides transportation to medical appointments.

- Bill Stumpf, Gateways Service Coordinator, works with three individuals enrolled in CareConnect. One man makes all decisions regarding his medical care; another individual relies on Bill to help him manage his health care. Bill describes the third man he supports as a "frequent flyer" who has spent more nights in the emergency room in the past year than he has at home. (He either takes a bus to the hospital or calls 911 and first responders get him to the ER.) Bill was on his way to pick this man up for the focus group when he got a call; his frequent flyer was in the emergency room and being admitted to the hospital.

Does health related mail (i.e. – appointment reminders, blood tests results, etc.) get sent directly to your family member or the individuals you support? If not – Who gets this information (parent or family member, guardian, case manager)?

- Barbara and Anita use *My DH* to electronically access their daughters' health care information. They both talked about how much they appreciated being able to have online access to appointment information, medical records, test results, and even doctors' notes.
- For participants who receive residential services from the Nashua Center, Plus Company, or IPPI, health related correspondence generally goes to the individual's group home or enhanced family care provider. In some cases, guardians receive this information and forward it to the agency. These agencies currently do not utilize *My DH*. Sheri Lupien is looking into getting consent from guardians to be able to access *My DH* for IPPI clients.
- Of the three CareConnect participants supported by Bill Stumpf, two individuals have medical correspondence sent directly to them. Bill receives all correspondence for one man.
- Members of the focus group discussed how incredibly helpful it would be to work with a Health Service Coordinator who had access to all the individual's medical information. Having someone who is a point of contact for families, service agencies, and health care providers would be a major step towards achieving coordinated health care for individuals with disabilities.

disabilities aren't like us and don't feel things the way we do still persists.

- Several members of the focus group reported having had bad experiences in hospitals. Barbara was not allowed to go into the emergency room with her daughter, even though her presence would have calmed her daughter and made things easier for everyone. Billy Abbot and Nancy Ferrell said individuals served by the Nashua Center also had problems with emergency room care.

How well does your primary care doctor know your family member or the people you support? Does their doctor provide any special help to accommodate their disability or meet their needs? If yes – Explain what help their doctor provides?

- Everyone in the focus group said the primary care physicians treating their family member or the people in their program knew the individuals well and were more than willing to make needed accommodations. People cited a number of examples of how the primary care physician had been helpful including: 1) letting people by pass the waiting room and go directly to an exam room, 2) making a personal call to get a patient seen at the mental health center when the center had a three month waiting list, 3) speaking directly and respectfully to the person, 4) asking the parent or staff person accompanying the patient if they had questions or needed more information, 5) having great nursing staff who go out of their way to help, and 6) ending each visit by asking, "What else can I do? Is there anything else you need?"

Has the doctor for your family member or the individuals you support talked with them about what they need to do to get and stay healthy? Has their doctor set goals that they can work on to improve their health? Does your family member or the individuals you support have a health care plan in place to help them meet these goals?

- People in the focus group all reported the individuals they support receive a standard how to be healthy message from their doctor – *Don't smoke. Lose weight. Exercise regularly. Eat a balanced diet.* People were unaware of any specific, individualized health goals or a plan for meeting these goals. Focus group members all thought that having a written personal plan with specific goals would be helpful, both for the individual and for the family and staff who support them.

that needs to be addressed.

- People talked about problems getting test results and specialists' evaluations to the primary care physician in a timely manner.
- Darlene Foley reported that a woman served by the Plus Company had three prescriptions for Ativan from three different doctors.
- For individuals who are nonverbal or have problems communicating, it is critical that doctors talk to the person who really knows the individual. Darlene shared the story of a home provider who sensed that something was wrong with the person she supported. She called the doctor's office for an appointment and after going the standard list of questions, was told by the receptionist it didn't sound serious and she should wait and see how the person was doing in the morning. Fortunately, the home provider decided to take the man directly to the emergency room. He had had a heart attack.

Has your family member or the individuals you support ever been confused about the medications they take or about their doctor's instructions? If yes - Who do they talk with to clear up this confusion and get the information they need?

- Anita's daughter takes responsibility for following up if she has questions about medications or treatment. She recently called her doctor because the pharmacist had filled her prescription with pills that were the wrong dosage.
- Plus Company and IPPI have nurses on staff who are responsible for communicating with medical providers and clearing up any problems.
- At the Nashua Center DSPs call the doctor's office if there are questions. The Center also has nurses on staff who can provide consultation as needed.
- Bill Stumpf said one of the men he supports lives with a girlfriend and she makes those calls for him. Bill calls the doctor's office to clear up any confusion or get information for the other people on his caseload.

Would it be helpful for your family member or the individuals you support had someone who understands their situation that they can call when

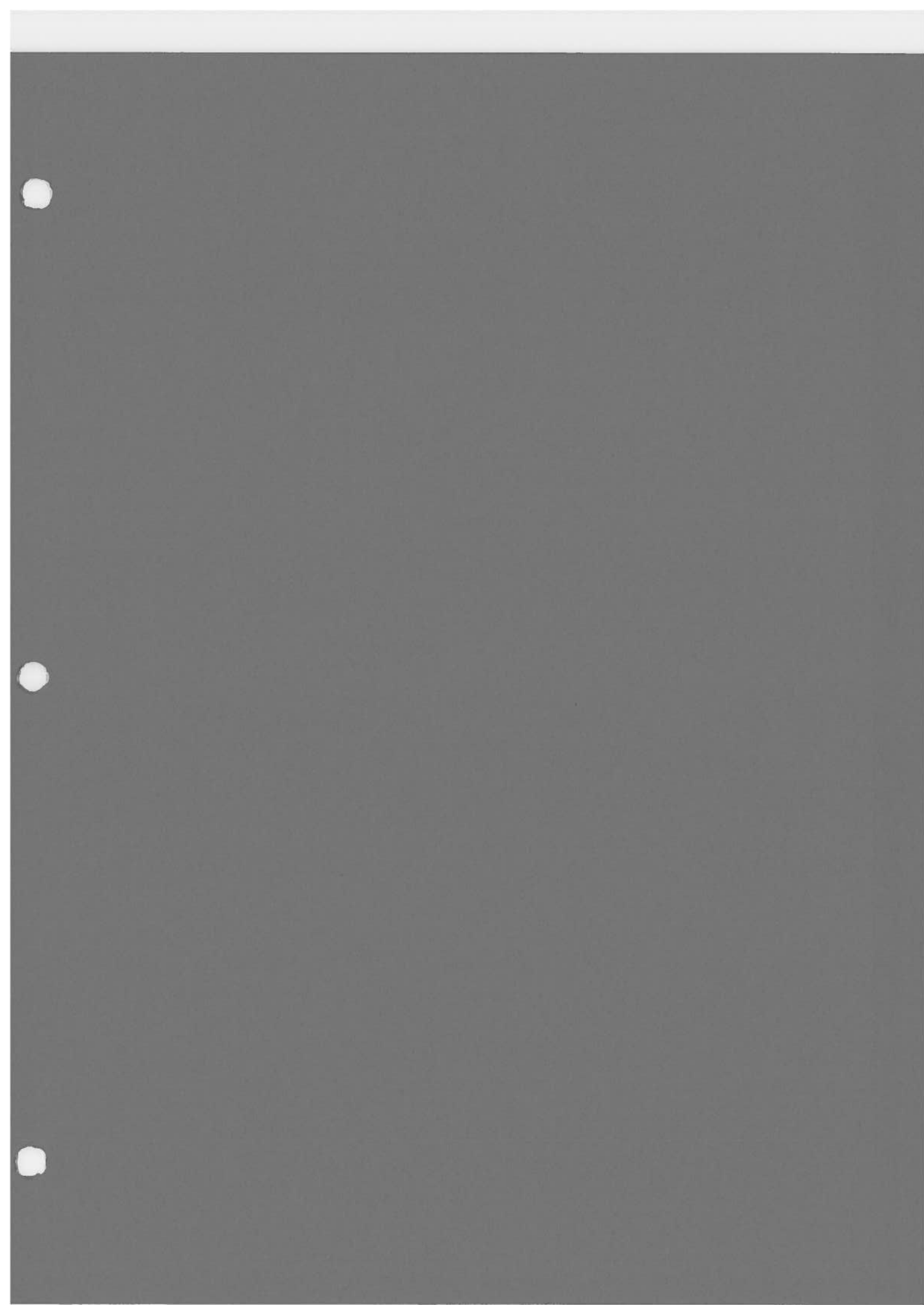
on” contact who identifies problems and hopefully, helps avert crises. These individuals are particularly vulnerable; Carolyn can be part of the safety net for this group.

- If the individual has a written health plan, Carolyn can help the person identify the steps they can take to take care of themselves and to be healthier.
- Carolyn should get to know the DSPs and enhanced home providers who support the individual. These people know the person best and understand what approaches will be most successful in working with the individual. This is information that will be helpful for Carolyn and that she can share with the individual’s health care providers.

What can Jessica Gagnon, the Health Services Coordinator, do to ensure your family member or the person you support has a good experience when they see their doctor or other health care providers?

- Jessica can play a critical role to help address the problem of poor communication and collaboration among health care providers.
- The most important aspect of the project will be to have someone who can keep track of people’s medical information and make sure things don’t fall through the cracks. This is especially critical for individuals on either end of the disability continuum - those with milder disabilities who are living independently and those with the most significant disabilities who have complex health care needs.
- Jessica can help the individual, family, and program staff to follow up on doctor’s recommendations. Barbara commented that she leaves the doctor’s office with a long list of things that need to get done. Having some one who checks in with her would make sure that things happen – like making sure her daughter gets a flu shot.

At the end of the evening focus group members talked about how excited they were about the CareConnect Project. They recognized that this pilot had the potential to significantly improve access to care and coordination of medical services for individuals with disabilities. Darlene Foley said, “I’ve been waiting since 1978 for something like this to happen. We need to bridge the gap between the doctors and families and caregivers.”



CareConnect
Participant Focus Group
Nashua, New Hampshire
November 21, 2013

To gain a better understanding of how individuals with disabilities access and utilize health care services, the CareConnect Disabilities Home Health Project held two focus groups. Initially, only one group was planned, however, at the last minute the two CareConnect participants who were to be part of this group were unable to attend. In order to capture the perspective of those who are participating in the project, a second focus group was held on November 21, 2013 at Gateways Community Services in Nashua. The group included three men enrolled in CareConnect: Bobby , an older gentleman with high blood pressure and back problems; Mike , a young man in his early 20's who has a congenital heart condition (he has had several open heart surgeries); and Chris , a man in his mid 30's who has a traumatic brain injury as the result of being hit by a car. Bill Stumpf, the service coordinator for all three men, and Ashley , Mike's wife also participated in this group.

Before the focus group began Carolyn McLaughlin, Community Navigator for CareConnect, spoke about her role with the project. As she was getting ready to leave Carolyn asked Mike who had recently been released from the hospital how he was doing. Mike told Carolyn that he had an appointment on Monday with his cardiologist at Boston Children's Hospital, but wasn't sure how he was getting down there. Before she left the meeting Carolyn made arrangements to drive Mike and his wife to Boston for the appointment. She told them that because they would be leaving Children's late in the afternoon she would speak with her mother who lives in the Boston area about dropping in after the appointment so they could have a comfortable place to wait out the rush hour traffic. Carolyn did not stay for the focus group discussion.

The focus group was presented with questions drawn up by the CareConnect planning team. The conversation was informal and comfortable. The members of the group all know one another well and the three men enrolled in the project all have the same primary care physician (Dr. Patel) at Dartmouth Hitchcock Medical Center in Nashua. The focus group's responses to questions are summarized below.

Questions about Your Health Care

Who do you talk to if you don't feel well or have a health care issue? Who decides if you need to see a doctor or go to the emergency room? How do you get to the doctor's office/hospital?

- Bobby calls his service coordinator Bill Stumpf when he isn't feeling well. Bill helps Bobby decide if he needs to see a doctor and will make the

his wife Ashley to come with him when he has an appointment. His wife said this works well, that she knows what Mike needs and can remember to bring up things that he sometimes forgets.

- Mike said when he goes to the doctors it's usually fine, but he recently had a bad experience with Dr. Patel's nurse practitioner. He made an appointment because he had a bad headache, but he also had other health problems that he wanted to discuss. The nurse practitioner was rude and wouldn't let him bring up the other things he wanted to talk about. She told him he was there to talk about his headache. Ashley was with her husband during the appointment and agreed that the nurse was not interested in listening to Mike and it was not a good experience.
- Chris said that sometimes he doesn't understand Dr. Patel and it helps to have Bill or another caseworker go with him to his appointments.

Have you and your doctor talked about what you need to do to get and stay healthy? Have you and your doctor set goals that you can work on to improve your health? Do you have a health care plan to help you meet these goals?

- The participants were not certain if they had a health plan or not.
- Bill reported that at the end of the appointment - whether it's an annual checkup or a visit about a specific health problem - Dr. Patel gives the patient and Bill a list of things they need to do, including information about medication, lab work, referrals to specialists, and a date for a follow up appointment.
- Mike said when he was younger he didn't listen to his doctors; he missed his appointments and ignored advice about what he needed to do to stay healthy (i.e. stop drinking, don't lift anything heavy). He said that he's changed, "Now I understand what I need to do to stay on this earth." Bill Stumpf agreed with Mike's assessment and told Mike he thought that he had really done a lot of growing up in the past year or so.

Do other health care workers – specialty doctors, people who draw blood, take X-rays, do mammograms, etc. - understand your needs and make accommodations? Have you had any problems with these health care workers? If yes - What were they?

- Bobby couldn't remember other medical appointments. Bill said he has taken Bobby for blood work and x-rays and that he's always been treated very well.
- Mike said Dr. Wu is very good about explaining things so he can understand them. He uses the white board in his office to draw a diagram of Mike's heart to illustrate what needs to be done. Mike also said he likes Bill

- Mike also said he needs to be careful about not lifting heavy things. He said is working on not drinking, but that it can be hard. He misses going to Slade's. Mike said his father and brother spend a lot of time at Slade's and will call and ask him to come over for a drink. Mike said he knows that it's not good for him to drink and he doesn't go there anymore.
- Chris said he is trying to not always call 911, but at night he gets scared. There are a lot of people in his building who are drinking and fighting and will bang on his door late at night. Ashley said she has a friend who lived in the same building who just moved because she didn't feel safe. Bill Stumpf is working with Chris to find another place to live. Bill said for the past seven weeks Chris has been attending a weekly anger management class at Gateways and that this has really helped him. Chris agreed and said now he knows if someone gets in his face he needs to walk away and not react.

What can Carol McLaughlin, the Community Manager, do to help you be as healthy as possible?

- Mike said it would be really helpful to have someone who can help him get back and forth to his appointments. His mother gives him rides, but she can't do that as much as she used to. Mike said it also will be good to have someone who keeps track of his appointments and can help him remember about what the doctor said and what he needs to do.
- Chris said he likes that he can call Carolyn if needs something and can check in with her if he has a problem.
- Bill Stumpf said he doesn't have the time to stay on top of everyone's situation and he doesn't always get complete information about his clients' medical issues. He believes having a central person who is responsible for this piece will make a huge difference for the people he supports.

*Respectfully Submitted November 21, 2013
Susan Covert, Focus Group Facilitator*

Gateways Community Services & Dartmouth-Hitchcock-Nashua **CareConnect Health Home Initiative**

Overview

What is the project?

Gateways Community Services and Dartmouth-Hitchcock-Nashua will collaboratively establish, effective January – April 2013, in a year one pilot in the Nashua region, a Health Home for 50 adults with developmental disabilities. The *CareConnect* Health Home will include an Integrated Care Coordination Team (ICT), on-site, enabling "line of sight patient management," at the Dartmouth-Hitchcock Nashua clinic, composed of a Gateways Community Services Health Service Coordinator (HSC), Gateways Community Navigator (CN), Dartmouth-Hitchcock-Nashua Care Managers, Primary Care Physicians, nurses, and specialists as needed. The ICT will work cooperatively to understand the practice population using data provided through nationally recognized reporting tools for functional and health assessment/reporting. The ICT will enroll the 50 patients (with a deliberate focus on at-risk patients as identified with the HRST or through anecdotal client history reported by Area Agency staff pending an HRST assessment) through outreach/education, share health and long term care information formally through an established permission for consent process, create a Developmental Disability Patient Registry through Dartmouth-Hitchcock-Nashua, and jointly produce individual results-oriented, measurable care plans (maintained in Dartmouth's electronic records by the care managers and/or RNs) for each of the 50 enrolled patients. Each enrolled patient will have an individualized care plan that addresses medical needs and long term community based supports, taking into account social needs, family/home support circumstance, and developmental disability functional level.

As part of the year one pilot, Gateways and Dartmouth-Hitchcock will design and test best practices specific to this target population, and specifically those enrolled in the *CareConnect* Health Home, for: 1.) hospital and emergency room discharge process, 2.) individualized, integrated care plans, and 3.) method for "at home" patient-specific follow up utilizing the support of a Community Navigator. All work products (see ***Deliverables*** section) will be available to the state along with a replication handbook for statewide implementation at the end of the year one pilot.

Please see Attachment A titled CareConnect-High Risk, High Need, High Cost.

Health Home – The Next Generation of Care for People with Developmental Disabilities

Health homes are a population-based integrated care model targeting consumers with chronic conditions, which coordinate medical and behavioral health care, and community and social supports.

The Patient Protection and Affordable Care Act (ACA), the health reform law enacted on March 23, 2010, provided states with a new Medicaid option along these lines – to provide "health home" services for enrollees with chronic conditions. Further, to encourage states to take up the new option, ACA authorized a temporary 90% federal match rate (FMAP) for health home services specified in the law. The health home option, established by 2703 of ACA, became available to states on January 1, 2011.

Health homes are designed to be person-centered systems of care that facilitate access to and coordination of the full array of primary and acute physical health services, behavioral health care, and long-term community-based services and supports. The health home model of service delivery expands on the traditional medical home models that many states have developed in their Medicaid programs, by building additional linkages and enhancing coordination and integration of medical and behavioral health care to better meet the needs of people with multiple chronic illnesses. The model aims to

illnesses are treated in separate facilities by doctors who do not communicate or work collaboratively with long term care providers. The need for a new delivery model is evident.

Both local New Hampshire and national evidence indicate poor outcomes riddled with unmet needs. The Centers for Disease Control and Prevention note that in 2012, on the 20th anniversary of the Americans with Disabilities Act, people with disabilities have poorer health overall, lack access to adequate health care, and have a greater risk for preventable health problems than the general population. Smoking and physical inactivity are more prevalent, and adults with disabilities far more frequently report fair or poor health than those with no disability. Adults with developmental disabilities represent a growing aging population, are often frequent users of emergency rooms, experience longer hospital stays, and have an increased burden with chronic illness.

In New Hampshire, according to the 2010 State of NH Medicaid Report, "persons with disabilities represent 16% of the population and account for 45% of total Medicaid program expenditures." While the mean PBPY cost for all NH Medicaid members is \$7,640, the mean PBPY cost for this specialized population is \$56,530 for all acute and long-term care cost. Current estimates are that 4,760 adults with developmental disabilities or acquired brain disorders are served through NH's Medicaid Home and Community Based Care waivers. Over half of these individuals are eligible for Medicare and Medicaid and are among the most costly participants to NH's Medicaid program.

Health Home – A Model for Savings and Sustainability

Savings – Savings are estimated at 5% in relation to acute care costs and .75% in relation to long term care costs according to preliminary research and estimates conducted by the Crotched Mountain Foundation Center for Medical Home Improvement in January 2012. Acute savings are estimated based on research literature of the impact of medical homes with integrated support to average patients – where savings often exceed 5%. Long term savings at .75% are estimated based on the lessening of intensity of staffing shown in the individual budgeting for all waiver recipients due to better access to healthcare and behavioral supports that will result from the improved health of enrollees. Please note that the Health Home model is new and as yet, empirically untested in the United States.

Many states are exploring this option. To get up to date information on Health Home Plan State Amendments, visit the Integrated Care Resource Center at:
[http://www.chcs.org/usr doc/State by State HH SPA matrix - 2812.pdf](http://www.chcs.org/usr_doc/State%20by%20State_HH_SPA_matrix_-_2812.pdf).

States with CMS approved Health Home State Plan Amendments that are moving into early adopter implementation include New York, Missouri, Rhode Island, and Oregon. North Carolina and Iowa were just recently approved by CMS. To learn more about these states and their applications, please review the August 2012 Kaiser Family Foundation report titled *Medicaid Health Homes for Beneficiaries with Chronic Conditions* as follows:
<http://www.kff.org/medicaid/upload/8340.pdf>

The Center for Health Care Strategies, Inc. has developed an ROI Forecasting Calculator for Health Homes. This is a web based tool created to help Medicaid stakeholders identify the cost savings potential for these new care delivery models. This tool walks users through a step by step process to develop ROI forecasts for health homes. Users enter detailed assumptions about their proposed Health Home including target population characteristics, program costs, and expected changes in health care utilization to estimate potential savings. By demonstrating the financial impacts of Health Homes beyond the up-front pilot and design costs, the ROI Calculator can also be used to create a financial case




Specific goals include:

- 1.) Implement and test an Integrated Care Coordination process that includes a care coordinator (from the Gateways Community Services developmental services system – Health Service Coordinator) and clinical staff of the primary medical home (Dartmouth-Hitchcock-Nashua), service coordination staff on the developmental services area agency, and a new role of Community Navigator in partnership with the patient, family, group home staff, and/or enhanced family care providers. When indicated, link medical and developmental services with behavioral health and home health agencies.
- 2.) Establish and test three Health Home best practices, for the developmental disability population, to:
 - a.) stratify, using national reporting tools, patient functional (Support Intensity Scale) and health assessment (Health Risk Screening Tool), b.) provide documentation for patient enrollment and consent, and c.) integrate planning methodology that establishes an integrated care plan with measurements in place.
- 3.) Redesign care protocols specific to the developmental disability population for 1.) hospital and emergency room discharge, 2.) preventive health action, and 3.) at-home follow up through assignment of Community Navigator.


Outcomes

What are the benefits of the project and what is your plan to measure this impact?



There is significant potential for individuals with developmental disabilities, and especially those with chronic health conditions, to **experience better care and improved health at lower cost**. Short term benefits include potential for fewer emergency room visits, reduced acute and long term needs with related costs, improved patient safety, more highly skilled medical resources with a greater understanding of the needs of the developmental disability population, and improved levels of shared decision making. Long term outcomes are improved quality of care, better care experience, more appropriate utilization of services, streamlined access, improved health and functional status, reduced disease and injury, and lower total cost of care. Moreover, the *CareConnect* initiative could be replicated statewide and sustained beyond the 50-person pilot to evolve into a managed care best practice for the entire developmental disability population in alliance with New Hampshire's managed care implementation.

CareConnect will target in the pilot, 50 individuals eligible for services under Home and Community-based care waivers. All improvements in health or health care (improved chronic disease indicators, preventive care, function and/or satisfaction) will have a positive impact on this population and reduce their health disparities. Better coordination of care and services across medical behavioral, home health, and community long term supports will have a positive effect on co-morbidities and their interrelated impact on health. Use of standardized, nationally recognized profiling for functional and medical assessment across the population will be crucial to the project in pilot and for the potential for follow-on replication and sustainability throughout the state of New Hampshire. Improved access to the primary medical home, assistance with healthcare utilization decisions, and closer monitoring of health status will reduce costs through fewer emergency room visits hospitalizations, redundant tests and other waste, and most importantly, overall health.



Gateways and Dartmouth-Hitchcock-Nashua will **measure the early impact for care redesign and targeted case management**. Specific areas to measure quantitatively will include: 1.) a reduction in hospital and emergency room admit rates and 2.) a reduction in re-admission hospital and emergency room rates. Qualitative measurement will include the effectiveness (satisfaction level) of self and assisted management of at home action plans with the support of the Community Navigator (for example, preventive care up to date for all Health Home patients and the care plan is accurate, timely).

CareConnect Health Home

Better Person – Centered Health Care, Improved Outcomes, & Lower Cost

